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THE UNIVERSITY OF ALBERTA

CONSUMER RIGHTS AND NURSING

by

© JANET L. STORCH

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF HEALTH SERVICES ADMINISTRATION

DIVISION OF HEALTH SERVICES ADMINISTRATION

EDMONTON, ALBERTA

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DEDICATION

To my husband Don, whose love, understanding and assistance enabled me to fulfill a dream; and to David, Michael and Jolan, three children who tried very hard to be helpful, and were.

ABSTRACT

The purpose of this study was to provide a background study for the use of nurses, and other health professionals, in examining consumer rights in health care.

The approach used was that of a social analysis using current and historical data; the technique employed was that of a scholarly analysis of the literature.

Seven major societal changes, identified by Roland Warren, were employed as the basis for analyzing changes in society, in health care organization and in nursing: division of labor, differentiation of interests and association, increasing systemic relationships to the larger society, bureaucratization and impersonalization, transfer of functions to profit enterprise and government, urbanization and sub-urbanization, and changing values.

Growth of human rights concerns, with particular reference to Canada; the emergence of a new consumerism; and the refinement of community development processes were examined as reactions to changes in society. Consumer rights issues in health care were examined as part of the same reaction to change, this time related to the health care system. The right to information, the right to respect, the right to participate, and the right to equal access to health care were discussed as the central concerns in consumer rights. The role and function of the patient representative, a new worker in health care, was compared and contrasted to the role and function of the legislative ombudsman.

A brief analysis of nursing, past and present, discloses both areas of strength and areas of weakness affecting nursing's ability to be responsive to consumer rights in health care. While nursing has evidenced considerable interest in consumer rights issues, it would seem that nursing has been almost immobilized in acting on these concerns by an inability to grapple with the problems of nursing itself.

It was concluded that nursing must strive to overcome the problems within nursing, re-assume a vital role in consumer advocacy, and above all implement consumer rights in health care and in nursing. Failure to act is to jeopardize the consumer's realization of his rights in health care, and to jeopardize the future development of nursing.

Thirty-four recommendations are given, primarily focused on nursing implementation of consumer rights.

ACKNOWLEDGMENTS

The completion of this thesis would not have been possible without the encouragement and support of many people. Special acknowledgment is made to Dr. Shirley Stinson, my advisor, for her encouragement, enthusiasm and guidance throughout the project, and during the past years. While the writer has had a longstanding interest in select aspects of consumer rights in health care, it was Dr. Stinson's idea to examine in breadth the issues, trends, and problems in consumer rights. For the learning opportunities her suggestion afforded, I am truly grateful.

Thanks to my committee members, Professor Gerry Gall and Professor Ellen Jacobs. Professor Jacob's initial encouragement of the project led me to Professor Gerry Gall whose enthusiasm, willingness and fund of knowledge have been most helpful.

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PART I

INTRODUCTION

CHAPTER I

INTRODUCTION

Within the past thirty years, the notion of "rights" has received growing recognition. Rights of women, rights of racial minority groups and rights of consumers have been some of the foci of rights concerns. Common to all of these claims to which individuals and groups feel entitled, are the rights to be equal and have full participation, the rights to information and the sharing of information, and the rights to access of power.[1]

Concern for rights has been felt throughout the world but particularly in North America, where that theme has permeated most areas of human endeavor including the health care industry.

> The opportunity to receive the benefits of medical science and enjoy good health has become a basic human right. It has been articulated from the podium of the United Nations and the doorstep of the country store.[2]

In striving to exercise their rights to health and health care, consumers have met with a health care delivery system structured for needs expressed by professionals rather than the "requirements of the citizens."[3]

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[1]Claire M. Fagin, "Nurses Rights," American Journal of Nursing 75:1 (January 1975): 82.

[2]Milton I. Roemer, Rural Health Care. (St. Louis: C.V. Mesby, 1976): 104.

[3]Joan M. Gilchrist, "The Nature of Nursing in the Health Care Structure," Nursing Papers 5:3 (December 1973): 3.

That some changes in health care delivery are required is undisputed. To what extent consumers will effect changes which will allow them the exercise of their rights is less clear. It has been postulated that ". . . the consumer action revolution may have a more dramatic impact on health care than any series of exotic scientific discoveries."[1]

Public dissatisfaction with present health services carries the threat that some power groups may lose their long held rights.[2] These groups include the health care professionals who have long supported the belief that the professional, not the consumer, is the best judge of services rendered.[3]

Isolated advocates have urged nurses to respond to the concerns for consumer rights in health care, but to date little evidence of more than tokenism for consumer concerns exists collectively.

> The professions that respond to societal changes most appropriately and most effectively are likely to expand in function and gain in status at the expense of other professions that do not.[4]

Nursing has not been notable in its ability to respond quickly to societal change. While we would be loath to encourage response to the

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[1]Lucie Young Kelly, "The Patient's Right to Know," Nursing Outlook 24:1 (January 1976): 26.

[2]Fagin, p. 85.

[3]Gwen D. Marram, "Patient's Evaluation of Their Care - Importance to the Nurse," Nursing Outlook 21:5 (May 1973): 322.

[4]Darwin Palmiere, "External Influences on Nursing: Political, Economic and Social Influences," in The Future is Now (New York: National League of Nursing, 1974), p. 11.

consumer rights movement for purposes of professional viability alone, nurses cannot afford to ignore consumer rights concerns because those concerns are the substance of nursing's professional belief.

Consumer Rights in Health Care

The phenomenon of consumer rights in health care requires definition in order to establish a common focus. Webster defines a consumer as "a person who uses goods or services to satisfy his needs rather than to resell them or produce other goods with them."[1] "A person who receives or has the right to receive goods or services or both under a consumer transaction. . ." is a definition of a consumer stated in an Alberta statute.[2] A consumer has also been defined as "a person living in a service area who meets all eligibility criteria to utilize services and is therefore a user or eligible potential user."[3]

Thus, embodied in the concept of the consumer is both the immediate user and the potential user. In most instances in health care, the immediate user is labelled 'the patient', while the potential user may be labelled consumer or citizen. For purposes of this paper, consumer, patient, and citizen will be used interchangeably.

The one word "right" has been used broadly and indiscriminately

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[1] Webster's New World Dictionary (Toronto: Nelson, Foster and Scott Ltd., 1960): 317.

[2] Unfair Trade Practices Act, R.S.A. 1975, c. 33.

[3] John Campbell, "Working Relationships between Providers and Consumers," American Journal of Public Health 61 (January 1971): 98.

to denote a variety of legal relationships between persons. Privileges, powers, immunities, and the concept of rights with correlative duties are some of these meanings,[1] each of which are embodied, to a varying degree, in the issues of consumer rights.

Purposes of the Study

A growing trend towards the establishment of a principle of consumer rights in health care is indicated by a review of health care literature. However, no comprehensive analysis of the general literature, nor any such analysis with special reference to nursing, has been found.

In order for nurses, and other health professionals, to appropriately respond to consumer rights in health care, they must understand the multi-faceted nature of these concerns.

It would seem that since Nightingale's time, the ethic of treating the patient with respect has been integral to nursing. In this regard, consumer rights principles are not an entirely new idea. However, there would seem to be a void, or at best, only partial endeavors to examine consumer rights in health care related to the implications for nursing.

The purpose of this study is to provide a background study for the use of nurses, and other health professionals, in examining consumer rights in health care, and subsequently in formalizing mechanisms to

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[1]Wesley Newcomb Hohfeld, Fundamental Legal Conceptions (New Haven, Conn.: Yale University Press, 1919): 35-38.

effectively construct a new relationship with consumers.

> We professionals are at the beginning of a road to a new relationship with consumers, and it is reasonable that we begin at the level of what we do rather than what we are.[1]

The Approach

Consumer rights in health care is a complex social phenomenon both in its origins and continuance, and in the scope of issues involved. Therefore, a method suited to this type of study is that of a social analysis using current and historical data. The technique employed is one of "a scholarly analysis of the literature."[2]

The sequence of analysis deemed logically appropriate was: the examination of societal change, health care change and nursing change along with the development of consumer rights issues in society, in health care, and in nursing. On that basis, the study is divided into three sections: chapters two and three dealing with community change and selected dimensions of consumer rights; chapters four through six dealing with change in health professionals and health care organization, and consumer rights in health care; and chapters seven and eight dealing with change in nursing and consumer rights and nursing. In the last chapter the author provides a summary and offers conclusions and recommendations.

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[1]Lowell S. Levin, "Time to Hear a Different Drum," American Journal of Nursing 72 (November 1972): 2007.

[2]As described by Shirley M. Stinson, "Deprofessionalization in Nursing?" Unpublished Ed.D. dissertation (Teachers' College, Columbia University, New York, 1969): 9-10.

Limitations of the Study

Several key limitations of this study must be identified. First, the major portion of the study is confined to the United States and Canada since changes in society, health organization, health professionals, nursing, and consumer rights are relatively similar in these two countries, but cannot be generalized to all other countries. Secondly, the time frame of the analysis is largely post World War II since some of the most significant precipitating factors in rights and in consumerism, and some of the major changes in health care have occurred in this period. Lastly, because the phenomenon of consumer rights in health care and in nursing is very complex, the treatment of the subject in this study cannot claim to be comprehensive, but rather illustrative of the issues involved.

PART II

SOCIETAL UNDERPINNINGS

CHAPTER 2

COMMUNITY CHANGE

Because new ideas, causes or concerns do not transpire in a vacuum, it would seem important to examine the society, or community at large, within which the consumer rights movement is occurring. By the same token, this society cannot be visualized as a static entity but as a society or community in change.

Roland Warren provides a framework through which to examine the changing nature of society today.[1] He speaks of seven major changes described as the following: 1) division of labor; 2) differentiation of interests and association; 3) increasing systemic relationships to the larger society; 4) bureaucratization and impersonalization; 5) transfer of functions to profit enterprise and government; 6) urbanization and suburbanization; and 7) changing values.

While these seven changes are not seen by Warren as exclusive, in his opinion they are considered to be the most significant changes in communities today in the Western world. As such, they provide us with a useful background against which to consider consumer rights. Though overlapping in their effects, each change will be reviewed separately.

Division of Labor

The accumulation of scientific and technical knowledge has led

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[1]Roland Warren, The Community in America (Chicago: Rand McNally and Company, 1972), p. 54.

to technical innovations of unprecedented diversity.[1] As a result of these changes, man has been forced to specialize and sub-specialize. Thus, he develops one specific and narrow "task" in which he becomes expert. The net result is a complex system of highly specialized individuals who are units of a system.

Extreme division of labor tends to produce individuals who fail to understand or appreciate the whole of which they are a part. Fragmentation in delivery of goods and services may result from such division.

Differentiation of Interests and Association

Whereas in times past, most of an individual's interests and associations centered on his immediate locale, and were interests held in common with his neighbours, outside interests and associations now tend to dictate the basis of an individual's loyalty and participation regardless of locale. Much of the time an individual spends with people, whether at the office, the lodge, the P.T.A., the union, or at the church, he spends with people he does not necessarily know well but with whom he shares an interest in a particular segment of the larger culture.[2] Individuals' lives can easily become segmented by their various involvements, and a lack of care and concern for others may occur because no one knows the total person.

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[1]H.C. Kahn and A.J. Werner, The Year 2000 (New York: Macmillan Company, 1967), pp. 50-57.

[2]Warren, p. 63.

Increasing Systemic Relationships To the Larger Society

At one time, local communities sustained a high degree of independence from outside influence and domination, had co-terminous boundaries for the various services provided, had community members who held a strong psychological identification with the community, and had strong horizontal or 'gemeinschaft-type' linkages. In contrast, a dominant aspect of communities today is the relationships they have with larger society - the vertical or 'gesellschaft-type' linkages.[1]

Businesses, clubs, churches, health and social service agencies rarely function as local entities without some outside affiliative body, or source of income, to whom they are then accountable.

> Many of these organizations are much more integrally a part of their respective extra-community systems than they are of the community in which they are located. And in many instances, the seat of decision-making is not within the local community but rather on a district or national decision-making level, centralized to promote coordination of the various parts of the system operating in communities across the face of the country.[2]

Decisions, then, which will affect a community and the daily needs of its residents, may be made several hundred miles away, and may be totally unsuited to an individual community because of a

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[1]The reality of these extra-community or vertical linkages is demonstrated clearly by two analytical studies, namely, Arthur J. Vidich and Joseph Bensman, "Small Town in Mass Society" and W. Lloyd Warner and J.O. Low, "Yankee City Loses Control of its Factories" in Perspectives on the American Community: A Book of Readings, pp. 201-213 and 214-220 respectively. Edited by Roland J. Warren (Chicago: Rand McNally Company, 1966).

[2]Warren, p. 63.

decision-maker's attempt to standardize procedures in all communities in a given area.

Yet another by-product of the vertical linkages is seen in the variety of service boundaries any given community may be subjected to, dependent upon the types of services rendered. School districts, local governments, health units, telephone service areas, and parks and recreation areas may have entirely different though overlapping boundaries. Thus, the responsibility rests primarily on the consumer of services to determine within which boundary the required service may be obtained to meet his needs.

Bureaucratization and Impersonalization

Bureaucracies are one of the most efficient means for organizing and administering the complex systems of our society.[1] Typically, bureaucracies are characterized by a hierarchy of authority, specialization, a system of rules, and impersonality.[2] The hierarchy of authority allows for lines of communication to obtain information and transmit directives; specialization requires effective coordination; a system of rules ensures that the myriad of workers conform to prescribed standards; and impersonal relationships assure the necessary

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[1]Talcott Parsons, "Introduction" in The Theory of Social and Economic Organization, p. 58. Author, Max Weber (New York: Collier-Macmillan Ltd., 1947).

[2]Weber, pp. 329-336.

detachment for efficiency to govern administrative decisions.[1]

While acknowledging that the above characteristics of a bureaucracy are essential to accomplish large scale organization, these characteristics become problematic to society when they become a threat to democratic ideals. The excessive centralization costs the individual person in terms of red tape, buck-passing, inflexibility, and impersonalization. In that people may do things in the name of an organization or authority that they would not do under their own moral code,[2] the benefits of bureaucracies are seriously beset by abuse of the very characteristics which make them rational solutions to the handling of complex problems.

In addition to the effects bureaucracies may have on consumers, the employees of a bureaucracy are profoundly affected by their relationship to the organization. William Whyte described the "organization man", product of modern bureaucracy, as someone who works for, and belongs to the organization. He further elaborates on the far-reaching effects this loyalty has on the family unit.[3] Twenty years have elapsed since Whyte penned his ideas. During this time,

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[1]Peter Blau and Marshall W. Meyer, Bureaucracy in Modern Society 2nd Edition (New York: Random House, 1971), pp. 8-9.

[2]An example of this discrepancy is shown from the research conducted by Millgram, briefly summarized in Harold J. Leavitt, Managerial Psychology 3rd edition (Chicago: University of Chicago Press, 1972), p. 138.

[3]William H. Whyte Jr., The Organization Man (Garden City, New York: Doubleday and Company, Inc., 1956).

society has witnessed a growth, both in size and number of organizations. It may be assumed that there has been a parallel growth in bureaucracy and organization men.

Transfer of Functions to Profit Enterprise and Government

Education of children, care of the elderly, care of the sick and the dying, as well as food preparation, dressmaking and home building, are functions once largely performed by families. Increasingly these functions are being transferred to profit enterprise and government. Schools, homes for the aged, hospitals, restaurants, clothing manufacturers, and construction firms are tangible proof of such transfers for the provision of goods and services. Many of these transfers were made some time ago: others are more recent.

When one surveys the continuum of functions, those performed by family to those carried out by government, the voluntary sector may be seen as occupying an intermediate position. The dilemma of voluntary agencies and associations in North America today attests to the continued transfer of functions to government and profit enterprise. A recent nationally commissioned report in the United States reveals that the voluntary sector is experiencing economic strains which predate, and are more severe, than the economy as a whole.[1]

Since voluntary agencies involve the local citizenry, they

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[1] Giving in America. Commission on Private Philanthropy and Public Needs, Washington D.C., 1976.

represent an opportunity for local autonomy and citizen input. If transfer of some of the functions performed by such agencies to government cannot be avoided, at least a citizen/consumer input mechanism to government would seem essential.

Urbanization and Suburbanization

Urbanization and suburbanization are part of the same process of spatial distribution of a population. The past years have seen a spectacular acceleration of this process in the growth of cities, and in changing social structures and behavioural patterns associated with city living. Kahn and Werner predict that the process will continue so that by the year 2000 one-half of the United States population will be located in three "megalopolises" - Boswash (Boston to Washington), Chipitts (Chicago to Pittsburgh), and Sansan (San Francisco to Santa Barbara).[1]

Many maladies have been attributed to urbanization, and many generalizations have been made about the urban personality. In general, disorganizing factors appear to be over-emphasized, and integrative factors overlooked.[2]

Lithwick contends that there has never been an adequate diagnosis of urban problems. Problems _in_ the city must be distinguished from problems _of_ the city. In other words, there is a need to separate

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[1]Kahn and Werner, p. 61.

[2]Noel P. Gist and Sylvia Fava, _Urban Society_ (New York: Crowell Publishing Co., 1974), pp. 435-436.

out of what is "urban" about urban problems.[1] For example, industrial pollution, unemployment, and inflation are problematic in the city, but are not genuinely urban-created problems.

Though suburbanization is part of the same process as urbanization, it is a reaction to the effects of urbanization, such as high land costs, impersonalization, anonymity, formalized status, and loneliness. In seeking the "village ideal", suburbanites attempt to escape the problems of city living while capitalizing on the benefits. Whereas a generation ago, a highly romantic picture of rural society served to emphasize the undersirable qualities of urban society, now suburbia becomes the contrast of "slavish conformity, fetish of togetherness, and a craze for organization" set against a romantic image of the city.[2]

In any case, suburbs tend to take two major forms: an industrial-employing suburb, or a dormitory suburb. The latter is the modal suburb, and by such separation of community of residence from community of work, suburbanization increases the phenomena of segmentation of individual lives.

Changing Values

Warren outlines his perceptions of the major value changes in society as the following: 1) gradual acceptance of governmental

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[1]N.H. Lithwick, Urban Canada: Problems and Prospects. A Report Prepared for the Honorable R.K. Andreas, Minister Responsible for Housing, Government of Canada (Ottawa, 1970), p. 20.

[2]S.D. Clark, "The Suburban Society" as paraphrased in Communities in Canada, p. 91. Edited by Leonard Marsh (Toronto: McClelland and Stewart, 1970).

activity as a positive value in an increasing number of fields; 2) gradual change from a moral to a causal interpretation of human behaviour; 3) change in community approach to social problems from that of moral reform to that of planning; and 4) a change of emphasis from work and production to enjoyment and consumption.[1]

Beyond these value changes, certain additional, often discrepant, changing values are evident. For example, devaluation of professional and institutional authority has occurred.

> Never before have the American people felt such universal distrust of their presumed leaders - whether in government, the law, the clergy, or education. After years of calculated deception over Vietnam, compounded by the conspiracy, skulduggery, and chicanery of Watergate, they now trust almost no one in authority.[2]

One should note that the effects of these mentioned events have not remained localized in the United States, but have affected many Western countries significantly.

Another, perhaps more fruitful value change is that the constructs and values of early industrial society seem to be gradually giving way to secular-humanistic outlooks. These outlooks stress dignity and worth, quality of life, and responsiveness to human needs by institutions; community as opposed to individual ends; and service ideals as opposed to egoism.[3] While some credit for this change in values may be given to

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[1]Warren, pp. 89-91.

[2]Warren Bennis, "Have We Gone Overboard on 'The Right to Know?'" Saturday Review 3 (March 6, 1976): 18.

[3]R.M. Battisella, "Rationalization of Health Services: Political and Social Assumption." International Journal of Health Services 2 (August 1972), p. 345.

the youth revolution of the late sixties as described in The Greening of America,[1] this change represents attempts to cope within the system, rather than what might be seen as the 'Greening' cop-out. Additionally, greater public awareness of the personal, sociological and psychological implications of technology has given impetus to public reappraisal of current value systems.

Greater valuation of equality appears particularly fundamental to the issues of consumer rights examined in this study. Equality of educational opportunity, equality of opportunity for health care, and equality of opportunity for women, embody value changes which have affected the position of both consumer and nurse.

Conclusion

The net effect of the seven major changes on society has been the creation of a society in which local communities are oriented to extra-community systems, local activities become controlled by outside interests, and individuals experience a serious degree of loss of control over their own lives. This loss of control is central to the consumer rights movement.

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[1]Charles A. Reich, The Greening of America (Toronto: Bantam Books, 1971).

CHAPTER 3

CONSUMER RIGHTS: SELECTED DIMENSIONS

Concomitant with societal change, three differing but converging main streams of influence appear to have affected the current awakening of consumer rights: 1) growth of human rights and civil liberties concerns; 2) emergence of a new consumerism; and 3) the refinement of community organization and community development processes. These selected dimensions will be reviewed in this chapter.

Before examining these issues of consumer rights, some basic philosophical questions must be addressed, namely, what is the nature of rights and how do we come to have rights?

The Nature of Rights

A thorough discussion of the nature of rights is beyond the scope of the present study. However, a cursory discussion would seem in order, if only to underline some of the major complexities of the concept.

Rights exist in society, that is, having rights occurs in a social world; however, the meaning of rights varies over time. Dias reviews the successive shifts in meaning which the word "right" has undergone, concluding that in the present time-frame, the word "right" connotes no fewer than four different ideas.[1]

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[1]R.W.M. Dias, Jurisprudence 3rd Edition. (London: Butterworths and Co. (Publishers) Limited, 1970): 241-248.

> In truth, the idea of right connotes a multitude of other ideas relating to behaviour patterns, not only of the 'possessor of the right' but also of other persons.[1]

Drawing on a scheme of rights and duties relations set out by Hohfeld, Dias discusses four variations of rights-duties relations. In the first case the "clue" to a right lies in the duty or obligation the existence of the right invokes in others. A second type of right refers to the freedom which a person possesses to do or not do something, which some have referred to as a privilege or a liberty. Power is a feature of the third type of right denoting the person's ability to alter a condition. The fourth type of right-relation denotes the freedom from the power of another.[2]

While each of these types of right-duty relations are evident to some extent in consumer rights, the first three would seem to be particularly relevant. For example, the right to health care invokes a duty or obligation in the health provider; the right to safety invokes an obligation in the police-force; and the right to an education invokes an obligation in the educators.

Questions of liberty, or freedom to exercise rights (the second type of right-duty relations) are questions addressed to the role of man in society. To what extent should our actions in society be subject to rule, or conversely, what are the "nature and limits of power which can be legitimately exercised by society over the individual?"[3]

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[1] Ibid., p. 248.

[2] Ibid., pp. 251-269.

[3] J.S. Mill, On Liberty (Markham, Ontario: Penguin Books Inc., 1974), p. 59.

Philosophers have debated this issue for many decades and the views range from a 'hands off'[1] view to one of substantial state power.[2] Liberties become increasingly threatened when the state seeks to exercise controls on, for example, lifestyle or environment.

The third type of right-duty relation has also become more significant by virtue of the "people-power" movements, which will be discussed later in this chapter.

Growth of Human Rights Concerns

Rights, then, pertain to the individual in relation to society. A growing trend has been evident of citizen insistence that the state assure the preservation of rights which have been given.[3] In the past century this trend became apparent following the First World War when knowledge of the suppression of human liberty in Russia, Italy, and Germany surfaced. The Great Depression accentuated the concern for rights, and the Atlantic Charter (1941) reaffirmed the rights of people to be free from want and fear.[4]

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[1]Ibid., p. 68.

[2]The Republic of Plato. Translated with Introduction and Notes by Francis Macdonald Cornford. (New York: Oxford University Press, 1959).

[3]W.F. Bowker, "Basic Rights and Fundamental Freedoms: What Are They? Canadian Bar Review 37:1 (March 1959): 43.

[4]Robert E. Asher et al. The United Nations and Promotion of General Welfare (Washington, D.C.: The Brookings Institute, 1957): 653.

Following World War II, the world became concerned with the need to safeguard human rights on the heels of Nazi and Fascist conflict and brutality, and the Nurenberg trials. More recently, segregation issues in the United States and the South African apartheid policy, and behaviour related to a perceived communist threat, have increased the concern for safeguarding rights.[1]

By 1948, the United Nations Declaration of Human Rights was adopted, representing the first inter-governmental statement on human rights in history, and symbolizing a deep concern in the post-war period to define rights.[2]

> . . . the Universal Declaration of Human Rights was a solemn affirmation of rights which had been trampled underfoot and a cry of protest against illegitimate, arrogant, cruel, and insensitive authority.[3]

While the Declaration was a non-binding resolution of the United Nations General Assembly, it was seen as an instrument containing goals and aspirations, rather than legally binding commitments.[4]

Some twenty years after the Declaration, two Covenants were adopted by the United Nations General Assembly, namely, the International Covenant on Economic, Social and Cultural Rights and the

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[1]D.A. Schmeiser, Civil Liberties in Canada (Toronto: Oxford University Press, 1964), Chapter 1.

[2]Asher, p. 667.

[3]J. Humphrey, "Human Rights and Authority," University of Toronto Law Journal 20 (1970): 415.

[4]Asher, p. 661.

International Covenant on Civil and Political Rights.[1] In 1976, Canada ratified the two Covenants.

Subsequent attempts by countries, states, and provinces to provide for the promotion of rights in the form of Bills of Rights (such as the Universal Declaration of Rights) have taken many different forms.

Bills of Rights

Bills or statements of human rights have been adopted in various countries. Examples of such statements may be found in the European Convention on Human Rights, the Nigerian Bill of Rights, the Commonwealth Bill of Rights, the Canadian Bill of Rights, and others. Some countries have appended human rights statements to their constitutions, (e.g., France and India).[2] The first ten amendments to the United States Constitution comprise the United States Bill of Rights.[3]

While the emergence of most of these bills has been coincident with or subsequent to the Universal Declaration of Human Rights (the United States being an exception), the characteristics of the bills vary with respect to intent, content, length, and degree of entrenchment.

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[1]See Ian Brownlie, Basic Documents on Human Rights (Oxford: Clarendon Press, 1971), pp. 199-231 for the actual resolutions which were adopted in 1966.

[2]Walter Surma Tarnopolsky, The Canadian Bill of Rights 2nd revised edition (Toronto: McClelland and Stewart Ltd., 1975), pp. 87-88.

[3]Kenneth R. Wing, The Law and the Public's Health (St. Louis: C.V. Mosby Co., 1976), p. 19.

Some bills may be statements of objectives to be pursued under the constitution, some are rules of strict law, and some are assertions of values which have normative implications. In regard to content and length, some are brief and very general, leaving wide scope for interpretation; others are lengthy and detailed with attempts to enumerate all limitations and exemptions in civil liberties. Bills also vary as to the ease with which they can be altered or repealed, dependent upon their constitutional status, which relates to the degree of entrenchment.[1] In most instances, enforcement of these bills or statements has been problematic.

In order to gain a better perspective on the growth of human rights concerns, including the problems surrounding enforcement of rights (i.e., within a single nation), discussion will now focus on human rights activities within Canada.

Provision for the Promotion of Human Rights in Canada

Activities in Canada aimed at human rights promotion paralleled activities throughout the western world. While Canadians felt concern for violations of human rights in other countries prior to 1939, noticeable interest in human rights and fundamental freedoms increased during World War II. Apart from the shock of the realization of civilized nations reverting to barbarity as evidenced by events in Europe, effects of the war effort in Canada were being experienced personally by Canadians.[2]

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[1]Tarnopolsky, pp. 87-88. [2]Ibid., p. 3.

> The resources of the nation were marshalled on a scale never before known. Orders in Council poured forth restricting economic freedom, freedom to criticize, freedom to move about. The government was omnipresent.[1]

In addition, a post-war awareness of violation of human rights on Canadian soil in the unjust treatment of the Japanese people in British Columbia, discrimination against the Jewish people, and a growing awareness of the impoverishing and degrading conditions of Indians and Eskimos, appear to have added to a concern for human rights.[2]

The enactment of the Racial Discrimination Act by the Province of Ontario in 1944 is generally accepted as the beginning of modern human rights in Canada. In 1947, the province of Saskatchewan enacted a more encompassing statute called the Saskatchewan Bill of Rights which dealt with human rights and fundamental freedoms. However, no provision was made, other than the "regular enforcement machinery of police and courts", to administer and enforce the Act.[3]

In the ensuing years, the majority of provinces passed fair employment practise acts (based on the first such scheme introduced in North America by the State of New York in 1945), fair accommodation practises acts, equal pay acts and age discrimination acts.

> However, this legislation continued to place the whole emphasis of promoting human rights upon the individual who has suffered

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[1]Ibid.

[2]D.A. Schmeiser, "The Effective Realization of Civil and Political Rights in Canada," Saskatchewan Law Review 33:3 (Fall 1968): 179-194.

[3]Tarnopolsky, p. 67.

> the most, and who is therefore in the least advantageous position to help himself. It places the administrative machinery of the state at the disposal of the victim of discrimination, but it approaches the whole problem as if it was solely his problem and his responsibility.[1]

In the sixties, most provinces moved to strengthen existing human rights legislation by the establishment of human rights commissions to administer the various human rights statutes. Recently, the Federal government has introduced a human rights bill which would establish a federal human rights commission.[2] These commissions are designed to take conciliatory action, remedial action, educative action and only punitive action if other attempts have failed. By their very nature, these statutes and resultant commissions are consistent with anti-discrimination legislation "while general human rights legislation, such as the Canada and Alberta Bill of Rights, is concerned with such matters as equal protection and due process of the law."[3]

Another significant Canadian advance in the area of human rights in the sixties was the passage of ombudsmen acts and the subsequent appointment of ombudsmen. The first of such acts was passed in Alberta early in 1967[4] followed by New Brunswick later in the same year.[5] Alberta established the first ombudsman office in the fall of 1967.

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[1]Ibid., p. 69.

[2]Edmonton Journal, November 30, 1976, p. 41.

[3]Gerald L. Gall, Address on the Canada Human Rights Act. Faculty of Law, University of Alberta, Edmonton, September 23, 1975, p. 1.

[4]S.A. 1967, c. 59, now R.S.A. 1970, c. 268.

[5]N.B.S. 1967, c. 18.

Ombudsman offices were created to receive complaints of two types, namely, "complaints against decisions taken where the authority had discretionary powers, and complaints against maladministration or official misconduct."[1] For example, the Alberta ombudsman is appointed as an officer of the Legislature and is free to investigate any complaint made to him by any person, or of his own motion, in matters relating to governmental administration where the proper channel of appeal has failed to satisfy a complainant.[2]

The Canadian Bill of Rights

In 1960, the Parliament of Canada passed an Act for the Recognition and Protection of Human Rights and Fundamental Freedoms, commonly known as The Canadian Bill of Rights. Passage of the bill was greeted with mixed reception, particularly by the legal profession who quickly perceived some of the major difficulties of enforcement of such a bill.[3] Adding to enforcement difficulties have been the limitations imposed by matters of federal and provincial jurisdictions. In addition, prevailing attitudes in judicial expositions have been that liberties have been protected by the Courts until now under Anglo-Canadian law and can continue to be protected in this way without assistance from Parliament.

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[1]Tarnopolsky, pp. 63-65.

[2]R.S.A. 1970, c. 268.

[3]Tarnopolsky, p. 10.

Others have argued that the Canadian Bill of Rights is an important and necessary bill which requires entrenchment to increase its authority.[1] A non-entrenched bill implies that the Bill of Rights makes no change in existing laws.[2] Schmeiser, writing in 1964, suggested that the Bill had promoted more liberal judicial decisions and had served as a powerful educative tool.[3] However, except for the famed Drybones case of 1970, which embodied the substance of the Canadian Bill of Rights in its judicial decision, the Bill has almost faded into oblivion in terms of its present impact.[4]

Other Civil Liberties Happenings in Canada

Two inquiries in Canada have promoted widespread attention to the whole issue of legislative restriction of rights and freedoms. The first inquiry was the Royal Commission Inquiry into Espionage in 1946, respecting the treatment of those suspected of passing state secrets to a foreign power. Those suspects had been denied the fundamental rights, including the right to retain counsel.[5]

More recently, reaction to the Ontario Police Bill gave rise to

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[1]P. Brett, "Reflections on the Canadian Bill of Rights," Alberta Law Review 7 (1969): 300.

[2]Mark R. MacGuigan, "The Development of Civil Liberties in Canada," Queen's Quarterly 72 (1965): 273.

[3]Schmeiser, p. 182.

[4]Gerald L. Gall, review of The Canadian Bill of Rights, by Walter S. Tarnopolsky, in Alberta Law Review 14:1 (1976): 193.

[5]Tarnopolsky, p. 2, 57.

a Royal Commission of Inquiry into Civil Rights, which was appointed in May, 1964. This Inquiry was charged with the tasks of examining, studying and inquiring into the laws of Ontario which affect personal freedoms, rights, and liberties of citizens to determine to what extent the legislature, government, boards, etc. encroached on these rights; and recommending changes in laws, procedures or processes as necessary in order to safeguard basic rights, freedoms and liberties of the individual.[1] The net effect of the latter Inquiry has been to focus attention

> . . . on the possibilities for infringement of civil rights through the administrative process; they have provided a simplified procedure for application for judicial review of administrative agencies, and they have helped to clarify the rules of natural justice by codifying them.[2]

Additionally, the very process of creating the Inquiry, which resulted from public reaction to the Police Bill, demonstrates the effect of public opinion as a safeguard to rights.

This belief, of public effectiveness in the promotion of human rights and civil liberties, has led to the growth of voluntary organizations, such as the Alberta Human Rights and Civil Liberties Association, whose objectives are the following:

1. To promote the understanding and observance of the United Declaration of Human Rights;
2. To encourage and foster among its members and the public, interest in and support of human rights and to take part in activities to further this objective;

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[1] Royal Commission Inquiry into Civil Rights, Report No. 1: Vol. I Province of Ontario, 1968, p. 1.

[2] Tarnopolsky, p. 63.

3. To encourage among its members and, where appropriate, to delegate officers and members to so act as to bring to public attention any infringement of civil liberties and to seek restoration and reconciliation in such situations;
4. To organize and sponsor lectures and programs to further the above objectives.[1]

Associations of this nature appear across Canada and the United States, usually members of a larger, national body which in Canada is known as the Canadian Federation of Civil Liberties and Human Rights Associations. The Saskatchewan Human Rights Association has been actively involved in many issues, including health care rights.

Emergence of a New Consumerism

Consumerism captured international attention in the late sixties and early seventies.[2] While the consumer's bargaining position has been a concern throughout time, the new consumerism has captured attention.

> It is new in the sense of fervor, public consciousness, the number of people actively involved, the charisma of certain of its leaders, and its obvious political appeal.[3]

U.S. Senator Warren Magnuson defines consumerism as the "Citizen's revolt against the unresponsiveness of both public and private institutions

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[1]Alberta Human Rights and Civil Liberties Association brochure, p. 1.

[2]Colston E. Warne, "The Worldwide Consumer Movement," in the 1970 Britannica Book of the Year, p. 504. (The Encyclopedia Britannica Inc., 1970). Warne describes the patterns of the consumer movement in Europe, Australia, Japan, Yugoslavia and the Philippines as similar to North American consumerism.

[3]Ralph M. Gaedeke and Warren W. Etcheson, Consumerism (San Francisco: Canfield Press, 1972), preface, p. xiii.

to human needs."[1]

Causes of Consumerism

While the current wave of consumerism is not unprecedented[2] the underlying causes of this present thrust may be many. One writer describes the consumer revolt as a re-assertion of the traditional American rugged individualism, plus a communal loss of faith in the responsiveness of corporate institutions.[3] Another sees the movement as a function of rising educational levels, increased use of leisure time, higher incomes and general affluence, increased quality expectations with increasing prices due to inflation, lower quality outputs resulting from lower unemployment, and the popular success achieved by Ralph Nader.[4] Yet another writer, a former Special Assistant to the President for Consumer Affairs, attributes the new consumerism as a factor of increased size in the marketplace conditioned by technological growth which outstrips the individual's ability to evaluate saleable products.[5]

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[1]Warren G. Magnuson, "Consumerism and the Emerging Goals of a New Society," in Consumerism, p. 3. Edited by Ralph M. Gaedeke and Warren W. Etcheson (San Francisco: Canfield Press, 1975).

[2]E.g., evidence of an earlier consumer movement is discussed in an article by Kenneth Dameron, "The Consumer Movement," Harvard Business Review 18 (January 1939), pp. 271-289. The central objective of the movement described is a demand of the consumer for information.

[3]Magnuson, p. 4.

[4]Richard H. Buskirk and James T. Rothe, "Consumerism - An Interpretation," Marketing 34 (October 1970), pp. 63-64.

[5]Betty Furness, "Establish a Department of Consumer Affairs," in Consumerism, p. 150. Edited by Ralph M. Gaedeke and Warren W. Etcheson (San Francisco: Canfield Press, 1972).

A survey of business leaders, government leaders, and consumer spokesmen regarding consumerism showed agreement on certain underlying causes of consumerism. The political appeal of consumer protection legislation, the impersonal nature of the marketplace, the confused language of advertising, the bandwagon effect, the greater public concern for social problems, the feeling that business should assume greater social responsibility, and the change in national attitude, were all credited with the rise in consumerism.[1]

In any case, the new consumerism is a product of many forces which reflect societal changes, particularly division of labor, bureaucratization and impersonalization, a transfer of functions to government and private enterprise, and changing values. It is ironic that one of the initial targets of the new consumerism centered on the auto industry,[2] the industry which initially perfected the division of labor beginning with Henry Ford.

Future of Consumerism

While earlier predictions saw the consumer movement as 'fizzling out', Gaedeke argues that it is viable and here to stay.[3] The role of the federal government in the United States regarding consumer rights was clearly envisioned by President John F. Kennedy in 1962 in his consumer message to Congress. Four basic consumer rights were enunciated:

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[1]Ralph M. Gaedeke, "What Business, Government, and Consumer Spokesmen Think About Consumerism?" in Consumerism, p. 96. Edited by Ralph M. Gaedeke and Warren W. Etcheson (San Francisco: Canfield Press, 1972).

[2]Ralph Nader, Unsafe At Any Speed (Viking Press, 1965).

[3]Gaedeke, p. 90.

1. The Right to Safety - to be protected against the marketing of goods which are hazardous to health or life.
2. The Right to be Informed - to be protected against fraudulent, deceitful or grossly misleading information, advertising, labelling or other practises, and to be given the facts needed to make informed choice.
3. The Right to Choose - to be assured, wherever possible, access to a variety of products and services at competitive prices and in those industries which Government regulations are substituted, an assurance of satisfactory quality and service at fair prices.
4. The Right to be Heard - to be assured that consumer interests will receive full and sympathetic consideration in the formulation of Government policy and fair expeditious treatment in its administrative tribunals.[1]

Since Kennedy's consumer rights statement, and as a result of governmental efforts to safeguard consumer rights, hundreds of consumer protection bills have been introduced in the United States and Canada. In addition, many corporate firms have provided mechanisms by which the consumer can communicate with management. While some of these attempts have been mere window-dressing to appease a restless consumer group,[2] consumer advocacy mechanisms in business and in government have increased as witnessed by the growing number of Consumer Affairs Departments.

The Alberta Government's Department of Consumer and Corporate Affairs is one example of a consumer advocacy agency which "provides a variety of investigative counselling, regulatory, and informational services" in order to advance the interests of Alberta consumers.[3]

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[1]Magnuson, p. 4.

[2]Joel Ross and Michael Kami, Corporate Management in Crisis: Why the Mighty Fall (Englewood Cliffs, N.J.: Prentice-Hall Inc. 1973), pp. 204-205.

[3]Alberta Consumer and Corporate Affairs, Annual Report for Fiscal Year Ended March 31, 1976, p. 3.

This Department administers the Unfair Trade Practises Act[1] which became law on January 1, 1976, and the Rent Regulation Appeal Board[2] which commenced operation early in 1976.

Consumer Responsibilities

While consumer rights have been central to the new consumerism, consumer responsibilities have remained peripheral. "The consumer has been conditioned to expect perfection from technology but not to the price this perfection costs."[3] In the seventies, consumer spokesmen have managed to shift the blame away from the consumer. For example, Magnuson maintains that Ralph Nader's most significant achievement in the auto safety controversy was in re-directing the attention of the public from "the role of the driver to the role of the vehicle."[4]

But not all consumers have shirked responsibility. A consumer group which has demonstrated responsible consumerism for over twenty years in Canada is the Consumer Association of Canada. This group may be partly a product of an earlier consumer movement, but certainly had its origins in the Second World War when the federal government enlisted the help of women's organizations to maintain price ceilings for the war effort. The success of these endeavors led to the formation in 1947 of the Canadian Association of Consumers for the purpose of developing

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[1]Unfair Trade Practises Act, R.S.A. 1975, c. 33.

[2]The Rent Regulation Appeal Board is established under Part 3 of the Temporary Rent Regulation Measures Act, R.S.A. 1975, c. 84.

[3]Buskirk and Rothe, p. 64.

[4]Magnuson, p. 5.

> . . . a more enlightened opinion on economic affairs and consumer interests; and to express this opinion in such a way as to benefit the home, the community and the nation.[1]

In 1962 the group adopted the name of the Consumers' Association of Canada (CAC). Through the exercise of responsibility in its statements and investigations, the CAC has established credibility as a voice for consumers and has managed to accomplish many changes in the labelling of products, packaging standards and sizing standards. In addition CAC has steadily urged the establishment of consumer affairs departments in governments.

> The activities of the CAC through the years have assisted greatly in bringing about today's new era of consumerism. Never before have manufacturers, retailers and governments been so conscious of the consumer as the person who is the keystone of the economy, nor consumers of their responsibility to make informed choices.[2]

In recent years the CAC has gone beyond product evaluation to concern for broader issues such as housing, pollution, and health. In 1974, the CAC issued a statement on consumer rights in health care, strikingly similar in design to President John F. Kennedy's consumer rights statement. The CAC Bill of Rights for Health Care will be discussed in greater detail in chapter five.

Community Organization and Community Development

A significant though minor stream of influence in consumer rights has been the development of community processes, variously known as

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[1]Consumers' Association of Canada - Brief History. Pamphlet of the Consumers' Association of Canada, p. 1.

[2]Ibid., p. 3.

community organization or community development, for the purposes of assisting citizens to regain some control over their lives. Whereas the consumer groups associated with Ralph Nader type activities may be seen as 'people power' in themselves, the difference proposed here is a "bottom-up" type of activity in the community, rather than a "top-down" activity as appears more typical of Nader type groups. The product of the community processes is the "professionalized" consumer who, by the process of education and motivation, becomes more competent to live with and gain some control over local aspects of a frustrating and changing world.[1]

Saul Alinsky typified the 'power for people' movement giving impetus to the idea of citizen involvement in shaping one's own world.[2] Alinsky would be classed as a radical community organizer who leads and assists but does not necessarily educate. In contrast, the community development process involves education, motivation and improvement of people, with the professional community development worker acting as a facilitator. Both in rural and metropolitan centres, projects in community development have regained for people, by the people, some degree of local or neighborhood control. In this way, community organization and community development, in particular, have provided for an exercise of consumer rights and responsibilities.

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[1]William Biddle and Loureide Biddle, The Community Development Process - The Re-discovery of Local Initiative (New York: Holt, Rinehart and Winston Inc., 1965), p. 34.

[2]Saul Alinsky, Rules for Radicals (New York: Random House, 1971).

Conclusion

The above three phenomena would seem to be the substance of the consumer rights movement today. The patient or client, as a consumer in the health care system, has certain rights which necessitate appropriate behaviour patterns on the part of health care providers in order to assure the client the exercise of those rights.

A comprehensive perspective on consumer rights in health care requires not only an examination of the societal context of human rights but an examination of the changing health care system. Attention is now directed toward that topic.

PART III

THE HEALTH CARE SYSTEM

AND CONSUMER RIGHTS

CHAPTER 4

HEALTH PROFESSIONALS AND HEALTH CARE ORGANIZATIONS: RELEVANCE TO CONSUMER RIGHTS

Societal changes have generated changes in the system of health care delivery.

> Growth of scientific knowledge, demographic change, higher educational levels, changing social values, and changes in family structure all have had an important impact on the medical care system. . . .[1]

Blishen speaks of change in the medical care system,which is a necessary but not sufficient part of health care. Medical care has changed, but even more striking changes are seen in the broader framework of the health care system.

In order to examine these changes more fully, the health care system will be considered in light of the seven major societal changes identified by Warren as discussed in chapter 2.

Division of Labor: Relationship to Professionalization

In few other fields of endeavor are the advances in scientific knowledge as apparent as in health care. For example, the application of the computer to care of patients has produced previously unimaginable treatment a diagnostic aides as well as health information monitoring systems. The aerospace program has had manifold implications for improved x-ray

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[1]Bernard R. Blishen, Doctors and Doctrines (Toronto: University of Toronto Press, 1969), p. 4.

procedures, equipment sterilization procedures, body temperature regulators, walking aides for the handicapped, various prosthetic appliances and a host of other improvements or innovations.[1] The above are not to discount the many advances in medical research and pharmaceutical research per se.

Scientific advances have served to create an increasingly complex technology in health care, resulting in a high degree of specialization and subspecialization of the labor force. Approximately 125 identified health occupations are now existent, each with two or three levels of classificatior personnel.[2] Of these health occupations, a good number have become "professionalized." The move towards professionalization is seen as an attempt

> . . .to introduce some order into the areas of vocational life which are prey to free-playing and disorganizing tendencies of a vast, mobile, and differentiated society undergoing continuous change. Professionalization seeks to clothe a given area with standards of excellence, to establish rules of conduct, to develop a sense of responsibility, to set criteria for recruitment and training, to ensure a measure of protection for members, to establish collective control over the area, and to elevate it to a position of dignity and social standing in the society.[3]

While many different descriptions of a profession exist, most writers agree that the essential components are a knowledge-skill

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[1]James O. Hepner and Donna M. Hepner, The Health Strategy Game (St. Louis: C.V. Mosby Co., 1973), pp. 252-260.

[2]Ibid., p. 171.

[3]Herbert Blumer, "Preface," in Howard M. Vollmer and Donald L. Mills, eds., Professionalization (Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1966), p. 2.

component, a service-ideal, autonomy, and a code of ethics.[1] Most would also agree that professionalization is a process that may affect any occupation to a greater or lesser degree.[2] Given that professionalization plays such a vital part in the organization and control of the health care system, it would seem important to consider briefly both the substance of a profession in general and the state of the health care professionals in particular.

The Substance of a Profession

Professionals are described as possessing a knowledge-skill component which is unique to the particular occupation. In distinguishing the type of skill a professional may render from the skill of a craftsman, Greenwood describes the skills of a professional as based upon a fund of knowledge, organized into an internally consistent system called a body of knowledge.[3] In order to acquire the knowledge and skills required, the professional undertakes extensive education of both an intellectual and a practical nature.

> Extensive education in the systematic theory of his discipline, imparts to the professional a type of knowledge that highlights

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[1]Shirley M. Stinson, "Deprofessionalization in Nursing?" (Unpublished Ed.D. dissertation, Teacher's College, Columbia University, New York, 1969), pp. 29-31.

[2]Howard M. Vollmer and Donald L. Mills, Professionalization (Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1966), p. 2.

[3]Ernest Greenwood, "Social Work," in Professionalization, Howard M. Vommer and Donald M. Mills, eds., (Englewood Cliffs, N.J.: Prentice-Hall, 1966), p. 11. This article was originally published under the title, "Attributes of a Profession," Social Work 2 (July 1957), 44-55.

> the layman's comparative ignorance. This fact is the basis for the professional's authority. . . .[1]

As the length of the education period increases, the professional identity and prestige of the professional increases accordingly.

Professional autonomy is an outgrowth of the unique knowledge-skill component, since, in the ideal type, only the professional and his colleagues are deemed competent to evaluate professional practise. The community, then, sanctions the right of self-government to the profession in order that the professional will safeguard public interest.[2] To distinguish the degree of competence implied by professional status, professional societies restrict membership to those able to prove competence by a system of licensure.[3] Thus, "the power to license is the power to restrict" entry into the profession.[4]

As an additional attempt to eliminate the unqualified and the unscrupulous from professional ranks, a profession is characterized by a code of ethics.[5] Such a code serves to identify the status of the professional and the client, specifies role obligations of the professional to the public, as well as role obligations to colleagues

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[1]Ibid., p. 12

[2]Ibid., pp. 13-14.

[3]Blishen, p. 15.

[4]J.T. McLeod, Consumer Participation, Regulation of the Professions, and Decentralization of Health Services. A Report submitted to the Minister of Health, Saskatchewan (Regina, Saskatchewan, August 1973), p. 65.

[5]Theodore Caplow, The Sociology of Work (Minneapolis: University of Minnesota Press, 1954), p. 139.

and clients.[1]

The code of ethics expresses the professional's service ideal which must be based upon the needs of the client, not on the self-interest of the professional.[2] The motivation underlying the service ideal may be altruistic, largely prudential, or both.[3]

The developmental steps in professionalization vary, but appear to follow a sequence generally described as the establishment of a professional association with definite membership criteria; formulation of a code of ethics which defines the service ideal; establishment of curricula for professional training; establishment of control of the training facilities (directly or indirectly) by the professional society, especially in regards to admission and final qualifications; and the promulgation of favorable legislation.[4] Goode maintains that all of these steps must be supported by the relevant public for an occupation to progress.[5] Of overriding importance in the progression towards professionalization is the shift from a part-time occupational endeavor to a full-time lifetime work.[6]

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[1]William Goode, "The Librarian: From Occupation to Profession?" The Library Quarterly 31 (October 1961), 315.

[2]Ibid., p. 308.

[3]Stinson, pp. 51-62.

[4]These steps in professionalization are described both by Theodore Caplow in The Sociology of Work, pp. 139-140, and by William Goode in "The Librarian: From Occupation to Profession?" The Library Quarterly 31 (October 1961), pp. 306-318.

[5]Goode, p. 308.

[6]Harold L. Wilensky, "The Professionalization of Everyone?" American Journal of Sociology 70 (September 1964): 142.

Health Care Professions

The health care professions represent a range of professions from the very old, classical profession of medicine along a continuum of new professions, semi-professions, marginal professions, to would-be professions. In that medicine is the prototype of professionalism, "the allied occupations tend to emulate it."[1] To a varying degree, then, other occupations have met various components of the professional criteria, but only medicine has managed to attain and retain a truly autonomous role. This autonomy has been sustained by its expertise in the division of labor which has established medicine as a dominant profession among health professionals.[2]

Hepner questions whether, in fact, medical dominance is based upon expertise or on charisma reflected in a high political strength characteristic of medicine; and further questions medicine's claim to authority and jurisdiction over all health issues when its achievements in these areas cannot be demonstrated.[3] Ivan Illich, philosopher-critic, states that there is "no evidence of any direct relation between improved health status and so-called progress of medicine." He brands doctor effectiveness an illusion.[4] Navarro contends that medical skills and

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[1]Hepner and Hepner, pp. 156-157.

[2]Eliott Freidson, "Dominant Professions, Bureaucracy, and Client Services," in Organizations and Clients, ed. William R. Rosengren and Mark Lefton (Columbus, Ohio: Charles E. Merrill Publishing Co., 1970), p. 77.

[3]Hepner and Hepner, p. 157 and 159.

[4]Ivan Illich, Medical Nemesis (London: Calder and Boyers Ltd., 1975), pp. 15-16.

trades only reinforce and legitimate power already present because of corporate class membership in society.[1] Haug concludes that medical power and dominance come from the system's bureaucratic arrangements rather than from the practitioner's medical degree.[2]

We have, then, a contradicting situation. Medicine achieves the characteristics of a profession when measured against other established professions, i.e., from a descriptive view. But medicine is criticized for its short-comings as a profession in totally applying its special competence to socially responsible uses, i.e., from a normative view.[3]

As a result of the proliferation of health knowledge translated into health services, new occupations are arising, and a two-way shift is becoming apparent. That group of occupations to whom duties or responsibilities of other professions have been allocated are one type, and that group of occupations which embody new specialization beyond the dominance of the established professions are another. Hepner labels the first type of process "subprofessionalization", and the latter process "centrifrugal specialization." He sees the medical profession as having an increasingly difficult time delineating its own territory as new knowledge gives rise to new specialties which challenge traditional lines of authority.[4]

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[1]Vicente Navarro, "The Industrialization of Fetishism or the Fetishism of Industrialization - A Critique of Ivan Illich," International Journal of Health Services 5 (1975), p. 363.

[2]Marie R. Haug, "The Erosion of Professional Authority: A Cross-Cultural Inquiry in the Case of the Physician," Millbank Memorial Fund Quarterly (Winter 1976), p. 102.

[3]For further elaboration on the two views of a profession, descriptive and normative, see Stinson, pp. 74-79.

[4]Hepner and Hepner, p. 159.

The net effect of medicine's continued dominance has been the perpetuation of a single-point entry into the health care system, which is the physician.[1] That a change in the organization and operation of the system through redefinition of roles is urgent, has been the plea of many.[2]

Another related effect of medical dominance has been the fact that no training program, however carefully conceived, can be utilized without the cooperation of the dominant profession.[3] In fact, accreditation of a health facility can be withdrawn if that facility engages in training unacceptable occupations.[4] The medical profession is in a strategic position of power in establishing new allied health occupations.

Those health professions which have been granted autonomy have the authority to control licensure. In that mandatory licensure contributes to rigid categorization of professionals, it often interferes with the ability of the health system to organize professionals to meet demands for patient services. Professionals become "locked in" to their particular positions.[5]

Furthermore, the public has for some time suspected some abuse of professional autonomy.

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[1]Madeline Leininger, "An Open Health Care System Model," Nursing Outlook 21 (March 1973), p. 172.

[2]For example, Anne Somers in Health Care in Transition: Direction for the Future (Chicago: Hospital Research and Educational Trust, 1971), pp. 94-96; Hepner and Hepner, pp. 161-164; Leininger, pp. 172-175.

[3]Hepner and Hepner, p. 158.

[4]Carol A. Brown, "The Division of Labor: Allied Health Professions," International Journal of Health Services 3 (Summer 1973), p. 438.

[5]Hepner and Hepner, pp. 164-167.

> The granting of self-government is a delegation of legislative and judicial functions and can only be justified as a safeguard to the public interest. The power is not conferred to give or reinforce a professional or occupational status.[1]

The medical profession, in particular, has been accused of self-interest, in that it acts through a variety of industry-wide organizations to maintain a division of labor to its advantage.[2]

Differentiation of Interests and Association

Durkheim described modern industrial society as having lost a general consensus of norms and values, but having become integrated by a division of labor which creates interdependence. In this way, social integration has become systematically arranged, and the key element in organic solidarity is the formal occupational association.[3] Goode further describes United States occupational life as characterized by communities of occupation (which he labels professionalism), each professional group having become a community without geographic locus.[4]

That the occupational association or the professional association can be classified as a community within a community, is apparent by their pervasive functioning. Roland Warren defines a community as "that combination of social units and systems which perform the major social functions having locality relevance."[5] These functions include production-consumption;

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[1]Royal Commission Inquiry into Civil Rights by Hon. James McRuer, Commissioner (Province of Ontario, 1968). Report No. 1, Vol. 3, p. 1162.

[2]Brown, pp. 435-436. See also, Illich, pp. 75-77.

[3]Vollmer and Mills, p. 47.

[4]William Goode, "Community Within a Community: The Professions," American Sociological Review 22 (April 1957), p. 194.

[5]Roland L. Warren, The Community in America (Chicago: Rand McNally and Company, 1972), p. 9.

socialization; social control; social participation; and mutual support.[1]

If one chooses the medical profession as exemplary, the socialization process occurs in medical training and collegial interaction;[2] and social control and social participation are also highly evident in the professional association structure[3] and in peer interactions. The effect a professional association may exert on the production-distribution-consumption of a particular service is manifest in the account of the doctor's strike in Saskatchewan,[4] and also evident in the many ways in which the medical profession acts as a pressure group to control the health care industry.[5] The mutual support function of the medical profession, the sense of brotherhood towards colleagues, is illustrated in medical codes of ethics.[6]

Apart from professional associations evidencing a powerful non-localized influence in health care organizations, the process of unionization of blue collar and white collar workers also has created substantial influence.

> The union movement in the hospital sector has been increasingly vigorous whereby presently virtually all hospital employees in Canada (with limited exceptions) are represented for collective bargaining purposes by a union or association.[7]

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[1]Ibid., pp. 9-10. [2]Blishen, chap. 3. [3]Ibid., chap. 6.

[4]Robin F. Badgely and Samuel Wolfe, Doctors' Strike (Toronto: Macmillan of Canada, 1967).

[5]M. Taylor, "The Role of the Medical Association in the Formulation and Execution of Public Policy," Canadian Journal of Economics and Political Science 26 (February 1960), 112-114.

[6]Charles J. McFadden, Medical Ethics (London: Burns & Coates, 1961), pp. 424-432.

[7]Maruice Le Clair, "The Canadian Health Care System," in National Health Insurance: Can We Learn from Canada? pp. 62-64. Edited by Spyros Andreopoulos (Toronto: John Wiley & Sons, 1975).

The reality of employees locked into certain job functions, with the health administrator unable to allocate staff positions with unfettered rationality, is perhaps nowhere as obvious as when one deals with union contracts and union demands.

A problem which arises from the differentiation of interests and association, which encompasses professional association and unions but is broader than both, is the problem of representation of various group interests in rationalization of health services. Battisella maintains that

> Whether consciously or unconsciously, professionals structure programs to suit their own need and convenience, and select problems which appear most exciting from the standpoint of expertise.[1]

Likewise, unions may be instrumental in resisting changes which would benefit patient care. Add to these two groups a public fractured across interest groups, fair representation becomes problematic.

Increasing Systemic Relationships to the Larger Society

Only brief comments are necessary here to serve as a reminder of the effects of this societal change on health professions and health care organization. The relationship of local professional associations to provincial, national and often international professional associations results in rapid awareness of changing patterns of care by means of these systemic linkages. Similarly, union achievements across the country and internationally are quickly conveyed to union locals.

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[1]R.M. Battisella, "Rationalization of Health Services: Political and Social Assumptions," International Journal of Health Services 2 (August 1972), p. 334.

The effect of these linkages may benefit the health care system, but may also interfere with the system as when, for example, reactions to salaried physicians are expressed from the context of British society rather than our own.

Bureaucratization and Impersonalization

Coinciding with the division of labor due to advancing technology is a process of institutionalization of health care. As a result of greater specialization of medical services, the introduction of complex equipment, and a greater delineation of employee roles, the average of 1.07 employees per patient bed in 1946 has risen to 2.5 employees per patient bed in 1970.[1]

> Of all present developments in the health care field, the emergence of the modern hospital has been the most dramatic and the most impressive example of institutionalization of medical care. Within living memory an age-old institution for the custodial care of the sick poor has emerged as the center of the medical world - a vast complex of expensive buildings, specialized equipment, and inter-disciplinary skills brought together for inpatient and outpatient care, research, professional, and general health education.[2]

This process of institutionalization leading to health care bureaucracies has not been without dilemma for both patient and provider. The impersonality engendered by bureaucratic operation has subjected the hospital, along with other human service organizations, to criticisms of failure to respond to the needs of the population they claim to serve;

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[1]Hepner and Hepner, p. 12.

[2]Somers, p. 27.

inconsistent and ill-organized service techniques; dehumanizing, degrading mechanisms to work with their clients; and ill-managed, wasteful use of public and private resource.[1]

The hospital, as the major bureaucracy in health care, stands in the rather unique position as a human service organization with a highly developed technology. In this way, hospitals differ from other service agencies in the dilemma of technological efficiency versus human service.[2] It seems little wonder, then, that concern for a greater measure of humane service has been the thrust of consumer concerns in health care.

The health professional, too, experiences the conflicting demands which work in the bureaucracy engenders. With professional commitment to a service ideal, the bureaucratic traits of specialization, a system of rules, a hierarchy of authority, and impersonality, place the health professional in conflict.

Scott describes the problems of professionals in bureaucracies as originating from two services.

> First, professionals participate in two systems - the profession and the organization - and their dual membership places important restrictions on the organization's attempts to deploy them in a rational manner with respect to its own goals. Second, the profession and the bureaucracy rest on fundamentally different principles of organization, and these divergent principles

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[1] Y. Hasenfeld and R.A. English, Human Service Organizations (Ann Arbor: The University of Michigan Press, 1974), p. 3.

[2] W.R. Rosengren and M. Lefton, Hospitals and Patients (New York: Atherton Press, 1969), p. 4, 44.

> generate conflicts between professionals and their employees in certain specific areas.[1]

Hepner also describes the conflict between the health care professional and the hospital as resulting from the fact that professional workers tend to identify more strongly with their profession than with the institution, yet the institution must have their services to survive.[2]

The culprit for depersonalization and loss of dignity for the individual consumer, according to Freidson, is not the bureaucracy but rather it is the product of professional organization.

> . . .many of the rigid, mechanical and authoritarian attributes and much of the inadequate coordination said to characterize the health services, may stem more from professional organization than from its bureaucratic characteristics. . . . . One kind of professional organization produces a non-bureaucratic but nonetheless real rigidity and authoritarianism which may be as much if not more responsible for the tribulations of the patient than the specifically bureaucratic elements of the health organization.[3]

Of the numerous communication problems in the hospital commonly attributed to the bureaucracy, Freidson would disclaim the view which attributes failure to communicate with patients to "underfinancing, understaffing and bureaucratization." Rather, professional organization of the hospital and the professional's conception of his relation to his clients are the causes.[4]

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[1]W. Richard Scott, "Professionals in Bureaucracies - Areas of Conflict," in Professionalization, p. 266. Edited by Howard M. Vollmer and Donald L. Mills (Englewood Cliffs, N.J.: Prentice-Hall, 1966).

[2]Hepner and Hepner, p. 241.

[3]Freidson, p. 74.

[4]Ibid., p. 80.

Absence of a single line of authority is another problem of the hospital bureaucracy. Authority is shared by the board of trustees, doctors, and administrators with doctors outside the lay-administrative line of control. Under these circumstances, coordination becomes difficult, and other health professionals employed by the organization find themselves responsible both to doctors, and to supervisors in the organization.[1] This formal dual authority structure has been particularly problematic for nurses.

Transfer of Functions to Profit Enterprise and Government

Closely related to the institutionalization of health care has been the shift of responsibility in health care from the individual or family to profit enterprise and to government, but particularly to government alone in Canada.

> Health care in Canada has been in a state of major transition for over a quarter of a century. The transition is from a mainly private [personal] responsibility for health care, supported by charity in cases of hardship, to an increasingly comprehensive public responsibility.[2]

This transfer of function has coincided with recognition of health and health care as a right rather than a privilege.

Canada gradually moved into a national program to remove barriers to health care beginning with grants for hospital construction in 1948, to the medicare program in 1968.[3] The transfer has both accentuated

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[1]Basil Georgepoulos and Floyd C. Mann, "The Hospital as an Organization," in Patients, Physicians, and Illness, 2nd ed., p. 309. Edited by E. Garthy Jaco (New York: The Free Press, 1972).

[2]Science Council of Canada, Report No. 22: Science for Health Services (Vancouver: Information Canada, October 1974), p. 18.

[3]Andreopoulos, p. 1.

the awareness of health care expenditure and has increased that expenditure.

> In addition to general inflation, forces driving medical costs upward include: union pressure for wage increases of non-physician health personnel, introduction of expensive new medical technology, absence of standards to judge what is to be considered an adequate level of medical care, and the lack of effective measures to contain costs.[1]

These problems in health care are not unique to Canada and largely constitute what has been labelled "the health care crisis." Acceptance of health care as a right has generated additional demands on health services and rising expectations of health services.[2]

Perhaps recognition of an "over-transfer" of responsibility to government was instrumental in the formulation of the working document A New Perspective on the Health of Canadians by the Minister of National Health and Welfare, which seeks to transfer some health responsibilities back to the individual. While personal responsibility is not a new concept, the impetus of the transfer of health care responsibilities to government seems to have precipitated some unrealistic consumer expectation requiring tempering.

> . . .people also still believe that health levels will improve with the amount spent on medical services, that mere medical interventions would be better, and that doctors know best what these services should be. . . . In the meantime, total expectations increase faster than resources for care.[3]

Illich describes the transfer of function of health care services

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[1]Ibid., p. 256.

[2]Somers, pp. 20-21.

[3]Marc Lalonde, A New Perspective on the Health of Canadians (Ottawa: National Health and Welfare, 1974).

[4]Ivan Illich, Medical Nemesis (London: Calder and Boyers Ltd., 1975), pp. 32-33.

as the "medicalization of life" which includes a "medicalization of expectations."[1] He sees these phenomena as having occurred because the health care system has become professional and physician-based, resulting in expropriation of the "power of the individual to heal himself and shape his own environment."[2] State support of such a system has only accentuated the problem.

Urbanization and Suburbanization

Defects in health care organization and distribution have been highlighted by the transfer of function to government. The organization and distribution of health services, especially primary services, and the supply and distribution of medical manpower, are two major problems.[3]

Distribution of services favors the urban and suburban centres (as well as certain regions of the country), rather than rural areas. While we might become complacent about this maldistribution because of a known rural to urban shift in population, we must keep in mind that though percentages have shifted, overall growth in national population has meant a rise in rural population.[4]

> In the early nineteenth century, cities were hotbeds of disease, mostly infectious. The rural areas, by contrast, were salubrious

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[1]Ivan Illich, Medical Nemesis (London: Calder and Boyers Ltd., 1975), pp. 32-33.

[2]Ibid., pp. 31-60 [3]Andreopoulos, p. 83.

[4]Milton I. Roemer, Rural Health Care (St. Louis: C.V. Mosby Co., 1976), preface p. v.

> places, and this was reflected by marked differentials in death rates among urban and rural populations. . . . Improvements in urban living conditions and health services have greatly reduced this differential.[1]

Though rural populations have a slightly lower overall mortality rate than urban centres, the burden of chronic disease is more prevalent in rural areas. In that health status relates not only to human biology and physical and social environments, but also to health services, the rural areas suffer most from deficiencies in health due to lack of health services.[2]

Shannon and Dever, in considering the spatial distribution of health resources, have drawn on the results of various studies to show these patterns. Since health resources rest primarily upon physician location, attention in their analysis was devoted to the patterns and reasons for location of physicians. A dual migration, rural to urban and urban to suburban, was noted in physician location.[3] Variables associated with the physician's decision to locate his practice in a given location were some of the following: location near hospitals, availability of housing, anticipated patient loads, and cultural and professional advantages.[4]

A Canadian study indicated a similar concern for the maldistribution of medical care to small communities, concluding that some eight

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[1]Ibid., p. 69.

[2]Ibid., pp. 70-79.

[3]Gary W. Shannon and G.E. Alan Dever, Health Care Delivery Spatial Perspectives (Toronto: McGraw-Hill Book Co., 1974), p. 60.

[4]Ibid., pp. 70-84.

million people in small communities in Ontario were without good comprehensive care.[1] Another Canadian study indicated that rural general practitioners do more complicated surgery than their counterparts in larger cities, and refer fewer patients to specialists.[2]

In addition to discrepant physician services, rural areas also suffer from shortage of nurses and other personnel; small, less well-equipped hospitals; a sparsity of out-patient services; and fewer special services (occupational health, special disease associations, etc.).[3] In order to provide better care to rural areas, and the urban core, regionalization is seen as a solution to problems of accessibility and availability. Regionalization is an integrated organization of health care services serving a delimited geographic area.[4] Through such organization, facilities are shared on an areawide basis with careful planning for various levels of care facilities throughout the area. In

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[1]Rex A. Lucas and A. Himmelfarb, "Some Social Aspects of Medical Care in Small Communities," Canadian Journal of Public Health 62 (January-February 1971): 15.

[2]S. Greenhill and H.J. Singh, "Comparison of the Professional Functions of Rural and Urban Practitioners," Journal of Medical Education 40 (September 1965), p. 859.

[3]Roemer, pp. 76-79.

[4]Thomas J. Boudreau, "The Regionalization of Health Services: Implementation and Research," in Health Care Research: A Symposium, p. 99. Edited by Donald E. Larsen and Edgar J. Love (Calgary: University of Calgary Bookstore, 1974).

this way, attempts are made to overcome urban-rural disparities.[1] Though the concept of regionalization has had extensive discussion, actual accomplishments so far have been spotty.[2]

Along with the problems of regional disparities are other problems associated with city living which affect health and the provision of health care. In the first half of the twentieth century, attention was directed to the pathological effects which cities as entities were supposed to have on individuals. These effects included lack of spontaneity, superficial impersonal relationships, instability, insecurity, mental strain, and many other pathologies.[3] Recent research has been directed at specific aspects of urban life and their relationship to pathology, recognizing that many variables influence health, behaviour and attitudes of individuals. Housing conditions, density, noise, and forced change have been some of the variables studied.[4]

While many of the studies concerning the above variables (and other variables) have produced uncertain results, there are certain patterns identified which result in poor mental or physical health.[5]

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[1]For further discussion of regionalization see H. Rocke Robertson, Health Care In Canada: A Commentary. Background Study for the Science Council of Canada (Ottawa: Information Canada, August 1973), pp. 100-106; Thomas J. Boudreau, "Regionalization of Health Services," in Task Force Report on the Cost of Health Services in Canada, Vol. 2, Appendix I (Ottawa: Information Canada), pp. 31-175.

[2]Roemer, p. 98.

[3]William Michelson, Man and His Urban Environment: A Sociological Approach (Don Mills, Ontario: Addison-Wesley Publishing Co., 1970): 148-151.

[4]Ibid., pp. 151-167. [5]Ibid., p. 167.

In addition, there would seem to be at least two effects of urban life central to consumer rights in health care. Support systems within families, extended families and neighborhoods would seem to be weaker than those of rural areas, creating a reliance on outside support systems, e.g., doctors, social workers, nurses, etc. Secondly, the volume demands placed on urban centre health facilities often outstrip provider capacity to provide personalized care and attention. Therefore, it is an interesting question as to whether the chances of abuse of consumer/patient rights might be increased in urban centres as compared with the chances of abuse of patient rights in the rural health care facility where patients are fewer in number and are often known to the providers.

Changing Values

Among the many value changes occurring over the past thirty years, two such changes have affected health professionals and health care organizations significantly. The increased value placed on health is one change with far-reaching consequences for rights to health care and rights to equality in health care. The issue of rights and equality will be discussed further in chapter five.

A declining value of professional authority is the second significant change. Haug postulates that a change in authority relationships is occurring between the public and professions in which knowledge is losing its role as a base of power.[1] The erosion of professional authority is manifest not only by individual patients

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[1]Haug, pp. 86-87.

questioning their physicians, but also by societal concern regarding the control of professional associations.

> Physician dominance is being questioned from the aspects of need as well as organizational policy. The relation of the health care system to society in general is being clarified. Provider dominance of the last quarter of the century is being challenged by such diverse organizations as labor unions, community boards, and federal, state, and local government.[1]

Governments in particular are beginning to question and to attempt to curb the power of the professionals. Examples of such moves are evident in at least three Canadian provinces. In 1973 the Province of Quebec adopted legislation which brought all professions in the province under one Statute known as the Quebec Professional Code.[2] The intent of the Code is to ensure the protection of the public through a variety of boards and councils; and by a multitude of regulations governing the conduct of professional corporations. Rozovsky describes Quebec's Professional Code as

> . . . the most sweeping attempt to enforce the public interest in control of occupations in Canada; spelling the end of self-governing of professions in order to serve the public interest.[3]

Ontario's Health Disciplines Act[4] is a much more limited piece of legislation aimed at strengthening the public accountability of five

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[1]William Lee Kissick, and Samuel P. Martin, "Issues of the Future in Health," Annals of the American Academy of Political and Social Science 399 (January 1972): 153.

[2]Professional Code, Statute of Quebec, 1973, c. 43.

[3]L.E. Rozovsky, "Health Professional Licensure: The New Dilemma," Dimensions in Health Service 52 (April 1975), p. 20.

[4]Health Disciplines Act, R.S.O., 1974, c. 74.

health professions: Dentistry, Medicine, Nursing, Optometry, and Pharmacy. Alberta is still considering the recommendations from a commission established by the government in 1973 on the rationalization of the development of professions and occupations.[1]

Conclusion

In this chapter the author has attempted to outline some of the major changes in the health care system influencing health professionals and health care organizations. These changes must be taken into account as the phenomena of consumer rights in health care are examined.

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[1] Report on Professions and Occupations II, by Catherine Chichak, Chairperson, Select Committee of the Legislative Assembly of Alberta on Professions and Occupations (Edmonton: Queen's Printer, 1973).

CHAPTER 5

CONSUMER RIGHTS IN HEALTH CARE

Changes in society have bred changes in the individual's relationships with the community system, including the health care system. This chapter will examine the growing commitment to health care as a right and the Patients' Bills of Right; the central issues and problems of consumer rights; and, briefly, the various associations in Canada promoting consumer rights in health care.

Health Care as a Right

> Today's society agrees that adequate health care is a right of all Americans, not just a privilege for a few who can afford to pay for it. The right to good health appears to have taken its place along with basic rights of freedom of religion, speech, press, and public assembly.[1]

If a society through its government claims health care as a right, the claim is pretentious unless means to exercise the right exist. Whose right, and whose responsibility to ensure the right, are serious questions.[2]

England, Sweden and other western countries have established political and social values which entitle all persons to access to personal health services regardless of their ability to pay for

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[1]James O. Hepner and Donna M. Hepner, The Health Strategy Game (St. Louis: C.V. Mosby Co., 1973), p. 1.

[2]Ibid., p. 2.

them.[1]

"Canada, along with many other countries, introduced health care plans based on the principle that health care is a right."[2] In 1964, the Royal Commission on Health Services in Canada enunciated a Health Charter for Canadians which identified the right of Canadians to good health services, and the obligation of the government to ensure the right.

> The achievement of the highest possible health standards for all our people must become a primary objective of national policy and a cohesive factor contributing to national unity, involving individual and community responsibilities and actions. This objective can best be achieved through a comprehensive, universal Health Services Programme for the Canadian people . . . .[3]

Not to be confused with the right to health care are two related rights often discussed, namely, the right to health and the right to be sick. The right to health generally implies the right to a state of complete physical, mental and social well-being as defined by the World Health Organization.

The claim to a right to health demands much beyond attention to health care as such, since it involves good housing, freedom from poverty, freedom from air polution, and basically, freedom from all the

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[1]Odin W. Anderson, Health Care: Can There Be Equity? (Toronto: John Wiley and Sons, 1972), p. 81.

[2]Lloyd F. Detwiler, "Social and Financial Effects of Health Care Programs," Hospital Administration in Canada 18 (December 1976): 13.

[3]Royal Commission on Health Services, vol. I (Ottawa: Queen's Printer, 1964), p. 12.

the evils which man falls heir to by reason of his humanness. Callahan argues that, indeed, the right to health, which implies the right not to be sick, is a claim which can only be entered against God himself (or evolutionary processes or nature) since one is entering a claim against the natural processes of disease and decay.[1]

Health as a right, then, is somewhat of a misnomer. Yet, a good part of the claim to rights in health care is confounded with the right to health.

The right to be sick is another related area of rights which was given impetus by Parsons' "sick role" concept. Parsons spelled out two major rights and two major duties of the sick person. The sick person, he states, has a right to be exempt from any responsibility for his incapacity, and also has a right to be exempt from normal social obligations. In return, the sick person has an obligation to try to get well, and to seek competent help. While Parsons' model may not be entirely applicable to certain illnesses (e.g., psychiatric illness, chronic illness, alcoholism, and terminal illness) these rights and responsibilities enunciated some twenty-five years ago have been largely unchallenged as a basic model for understanding the sick role.[2]

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[1]Daniel Callahan, "Health and Society: Some Ethical Imperatives," Daedalus 106 (Winter 1977): 30.

[2]Alexander Segall, "The Sick Role Concept: Understanding Illness Behaviour," Journal of Health and Social Behaviour 17 (June 1976): 162-169.

Consumers claim that human rights are endangered when the sick person enters the health care system. Rights as basic as considerate and respectful care, and informed consent, are rights which some consumers believe they must forfeit when they are the recipients of health care.[1] Others, not convinced that these rights should have been forfeited, seek re-dress for wrongs committed by failure, on the part of the professional, to observe basic rights.

One of the ways the individual may try to discipline a health professional is by complaint to the professional's licensing body. However, hearings are closed, and even if the professional is found guilty and disciplined, the complainant receives no monetary compensation.[2] He may, however, receive some psychological benefit from a sense of redress; and, in addition, he may have instigated action beneficial to other consumers.

Another way of seeking redress, becoming a subject of grave concern, is the malpractise suit. Malpractise suits have increased tremendously over the past few years. An estimated 7,000 to 10,000 malpractise suits are filed annually in the United States.[3] Creighton sees this increase related

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[1]Daisy L. Tagliacozzo and Hans Mauksh, "The Patient's View of the Patient's Role," in Patients, Physicians and Illness 2nd ed. Edited by E. Garthy Jaco (New York: The Free Press, 1972): 177.

[2]Penny Kome, "Patient Power," Homemakers (June/July/August 1976) :10. An exception to this general occurrence is found under the Professional Code of Quebec (Bill 250). A committee on discipline receives and hears complaints against a professional. The committee also has the power to condemn the complainant to pay a sum of money to the person entitled to it. (Division VII, Discipline: 4 Decisions and Penalties: Items 153-155).

[3]Anne R. Somers, Health Care in Transition: Directions for the Future (Chicago: Hospital Research and Educational Trust, 1971): 10-11.

to general societal trends which involve: 1) more people receiving care; 2) technical innovations and advances posing increased risk; 3) a public's unreasonable expectation of health care; 4) changes in practise involving less personal provider-patient relationships; and 5) a marked increase since World War II in all types of litigation, starting with automobile accidents. Disappointment with the results of health care also has caused consumers to turn to litigation as a solution.[1]

> To some extent . . . the rise in the number of malpractise suits in the United States seems not only to be a reaction to the errors and abuses that physicians can commit, but also a reflection of the degree to which the profession is being held personally responsible for the scientific and technical uncertainties and limitations of their discipline.[2]

The rationale for malpractise suits appears to be the following:

> . . . by holding a provider liable for malpractise, the law is attempting to control the quality of medical care. The threat of liability is supposed to act as an incentive to the provider to deliver care of sufficient quality. In theory, the patient who does not receive sufficient quality of care is at least compensated for any resulting damage.[3]

Unfortunately, these objectives are rarely achieved due to the practical realities of the legal system.[4] Further, it is a moot point as to

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[1]Helen Creighton, "The Malpractise Problem," Nursing Clinics of North America 9 (September 1974): 425-433.

[2]Renee Fox, "The Medicalization and Demedicalization of American Society," Daedalus 106 (Winter 1977): 11.

[3]Kenneth R. Wing, The Law and the Public's Health (St. Louis: C.V. Mosby Co., 1976), p. 91.

[4]An additional reality of the legal system, particularly in the United States, is that the system may also induce malpractise suits by the establishment of lawyer contingency fees in such suits.

whether restitution can ever be made for lost health.

In Canada some 30,000 doctors belong to the Canadian Medical Protective Association which generally defends doctors in malpractise suits. In 1975, 229 new legal actions were brought against doctor members, and of the 114 cases that reached court, only nine went against the doctor.[1] The losing party pays costs of the suit, making efforts at re-dress a costly endeavor. In addition, expert witnesses are required to establish medical negligence, and in many cases physicians are reluctant to testify against peers.[2]

In addition to litigation as an apparently ineffective method of assuring quality care (or obtaining re-dress for poor care) there is evidence that litigation has "back-fired" on the consumer. Firstly, costs of hospital care and medical care have mounted in accordance with malpractise premium rises. Secondly, to avoid high malpractise premiums, doctors have tended to order more diagnostic tests on patients (for the doctor's own legal protection), and general-practitioners, in particular, have quit offering certain medical services in order to fit into the low-risk category for malpractise premium purposes, e.g., radiotherapy and electroshock therapy.[3]

Marshall advises Canadian doctors that legal liability boils down to two main problems, namely, lack of consent and failure to take

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[1]Canadian Medical Protective Association, Seventy-Fifth Annual Report, June 1976, pp. 10-11, 22, 34.

[2]Kome, pp. 8-10.

[3]Arthur Owens, "How Much Have Malpractise Premiums Gone Up?" Medical Economics (December 27, 1976): 102-103.

reasonable care. He further advises that happy patients and families do not sue, therefore, the best line of defense is to build rapport with patients, answer their questions honestly, make regular visits to patients, and report errors honestly.[1]

While the behaviour advocated for physicians would seem a foregone expectation, the fact that it represents legal advice to doctors may in itself indicate that consumer rights in health care have been endangered. In recognition that these rights are in jeopardy, the American Hospital Association presented a Patient's Bill of Rights for health care rendered in hospital. Fox sees such a move to consideration of patient rights as an attempt to "destratify" the relationship of health care providers and patients, to make these relationships more open and egalitarian.[2]

Patient's Bills of Rights

While the American Hospital Association's Statement on a Patient's Bill of Rights, affirmed November 17, 1972, was not the first Patient's Bill to be advocated in the health care arena, it was received with much publicity, response, and reaction.

Not only was the American Hospital Association's Bill published

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[1]David T. Marshall, The Physician and the Law (Toronto: Medical Communication Services, 1974), pp. 50-51.

[2]Fox, p. 19.

broadly in professional journals,[1] but it was also summarized and discussed in popular magazines.[2] At the same time, the public was becoming increasingly aware of violations of basic human rights in the revelation of the HEW syphilitic study, and the sterilizations among mentally defective women. These mutual occurrences seem to have given the Bill the stature it received.[3]

The Bill contains twelve patient rights, summarized here as the following: 1) the right to considerate and respectful care; 2) the right to obtain from the physician information concerning one's own diagnosis, treatment, and progress; 3) the right to receive from the physician information necessary to give informed consent to any procedures; 4) the right to refuse treatment to the extent permitted by law; 5) the right to privacy concerning one's own medical care; 6) the right to confidentiality in all communications and records relating to one's own care; 7) the right to reasonable responses to requests for service; 8) the right to information concerning other health care and educational institutions related to one's own care; 9) the right to be advised if the hospital plans to perform human experimentation affecting one's own care and to refuse to participate in same; 10) the right to expect reasonable continuity of care; 11) the right to examine and

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[1]For example, the Bill was either published in total or summarized in Nursing Outlook 21 (February 1973): 82; International Nursing Review 20 (September-October 1973): 156; RN 36 (May 1973): 24; Health and Rehabilitative Library Science 1 (March 1975): 8.

[2]For example, Time 101 (January 15, 1973): 49-50.

[3]Nancy Quinn and Anne R. Somers, "The Patient's Bill of Rights - A Significant Aspect of the Consumer Revolution," Nursing Outlook 22 (April 1974): 240.

receive explanation of one's hospital bill; and 12) the right to know what hospital rules and regulations apply to his conduct as a patient.[1]

Effective August 1, 1973, the State of Minnesota was the first to establish a law requiring that all patients in Minnesota health care facilities receive a Patient's Bill of Rights, and that the Bill be posted conspicuously in health facilities. The Minnesota Bill was modelled after the A.H.A. statement, but excluded the right to refuse medical treatment, the right to refuse to participate in research, and the right to receive an explanation of the hospital bill.[2]

Other states followed suit in bringing similar bills before their legislature with varying results from rejection to endorsement of the Bill to law. Herbert S. Denenberg, Insurance Commissioner from Pennsylvania, published his own bill of patient's rights threatening to use the regulatory authority of the insurance department to see that it was implemented. The Denenberg Bill was titled, "Citizen's Bill of Hospital Rights: What a Patient and Public Can and Should Expect from Our Hospitals."[3] While also featuring twelve points, the Denenberg Bill was different in that it spoke to issues of quality of care, economy of care, consumer input and participation in the decision process, access to information and answers about treatment, personal dignity, control

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[1]"Statement on a Patient's Bill of Rights," Hospitals, J.A.H.A. 47 (February 16, 1973): 41. (See Appendix A.)

[2]"Minnesota Hospitals Must Tell Patients About Their Rights," (NEWS) Modern Hospital 121:10 (September 1973): 42.

[3]"Citizen's Bill of Hospital Rights issued by Denenberg," (News at deadline) Hospitals, J.A.H.A. 47:10 (May 16, 1973): 21.

of one's body and life, action on complaints and problems, disclosure of data about the hospital, disclosure of conflict of interest problems, access to information about stay and records of care, continuity of care and consumer advocacy.[1]

Within a short time following the A.H.A. Bill, the Minnesota Bill and the Denenberg Bill, other bills emerged including the Catholic Hospital Association's Bill which utilized the A.H.A. Bill but contained changes consistent with hospital moral and religious beliefs.[2] In addition, bills began to emerge specific to certain groups of people in health care, such as the Pediatric Bill of Rights,[3] the Crippled Child's Bill of Rights,[4] The Dying Person's Bill of Rights,[5] and the Michigan State Nurses' Rights.[6]

Canadian Patient's Bills of Rights

Activity in Canada in relation to patient's bills of rights has

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[1]Quinn and Somers, p. 242.

[2]"Catholic Hospital Association Board Issues Guidelines for Patients' Bill of Rights," Hospital Progress 54:7 (July 1973): 19.

[3]"Children's Hospitals Issue Bill of Rights," (NEWS) American Journal of Nursing 74:6 (June 1974): 1005-1006.

[4]"The Crippled Child's Bill of Rights," Health and Rehabilitative Library Services 1:1 (March 1975): 9.

[5]"The Dying Person's Bill of Rights," American Journal of Nursing 75:1 (January 1975): 99.

[6]Claire M. Fagin, "Nurses' Rights," American Journal of Nursing 75:1 (January 1975): 82-85.

paralleled that of the United States, on a modified scale. Nova Scotia appears to have been the first province whose major health professionals publicly supported the AHA Bill as one step to improve communication between patient, family, and members of the health team.[1] A joint committee of representatives from the medical society, provincial registered nurses' association, provincial hospital association, and others began in early 1973 to draw up a Bill of Rights for Patients which was completed as a thirteen point protocol by December 1973.[2]

In Ontario the Pickering Report, published in April of 1973, recommended development of a "Patient's Bill of Rights for Medical Care and Services."[3] The purpose given for such a bill was to crystallize "what most doctors already feel" and to represent the Ontario Medical Association's first statement of its official acceptance of the fact that the public does have clear rights in medical matters. Pickering's suggestions were subsequently dealt with in a Citizens' Advisory Committee of the Ontario Medical Association, modified by the Association's executive committee and board of directors, and subsequently rejected in a Council vote of 96-79. Reasons cited for rejection of this Declaration of Patients' Rights document were a fear of increased risk of malpractise suits, a feeling that the document overstates patient

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[1]"Bill of Rights for Patients to be Established in Nova Scotia," (NEWS) Canadian Nurse 69:3 (March 1973): 19-20.

[2]John Sansom, "Bill of Rights is Drawn Up," Medioscope (December 1, 1973): 1, 8.

[3]Edward A. Pickering, Report of the Special Study regarding the Medical Profession in Ontario (Toronto: Ontario Medical Association, 1973): 91-93.

rights, and a conviction that these rights are already enshrined in the Canadian Medical Association's code of ethics.[1]

In 1974, the Royal Ottawa Hospital adopted the A.H.A. Bill, with slight modifications.[2] Contents of the bill were to be included in staff orientation and development programs, and the document was to be distributed to all patients.[3]

Undoubtedly, the most significant document published in Canada was the Consumer Rights in Health Care resolution of the Consumers' Association of Canada. This resolution resembles the Consumer Rights statement by President John F. Kennedy discussed in chapter three, in its format of a four point charter. The four points are the

I Right to be informed
II Right to be respected as the individual with the major responsibility for his own care
III Right to participate in decision-making affecting his health
IV Right to equal access to health care.[4]

This charter, with elaboration on each point, has also been published and discussed in various professional journals,[5] and will constitute the basis of further discussion of consumer rights in health care in

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[1]"Patients' Rights Bill thrown out by O.M.A.," Medical Post 12:25 (December 7, 1976): 1, 29.

[2]"Ottawa Hospital Adopts Patients' Bill of Rights," Hospital Administration in Canada 16:12 (December 1974): 45.

[3]"Bill of Rights for Patients," Canadian Welfare 51:1 (January-February 1975): 18-19.

[4]"Consumer Rights in Health Care," Canadian Consumer 4:2 (April 1974): 1. (See Appendix B.)

[5]For example, Canadian Medical Association Journal 111:2 (July 20, 1974): 177 and Medioscope (December 1, 1973): 4.

this chapter. Before this discussion, however, a brief summary of reactions to the various bills is in order.

Reactions to Patient's Bills of Rights

Reactions to the A.H.A. Bill and subsequent Bills of Rights for Patients have been mixed, varying from enthusiastic response to grave concern about the implications . While some health care leaders have assumed universal acceptance of such a bill;[1] others have heralded it as an important step toward humanizing patient care.[2] Lawyers have raised concern about some of the practical legal questions involved since the burden of patient rights is thereby placed on the hospital, when in fact the active cooperation of the physician is necessary to ensure these rights.[3] In addition, the bill may lead to unjustified expectations by the public.[4]

George Annas, a leading civil liberties spokesman and lawyer, has criticized the current bills of rights in hospitals as having three characteristics: "They're provider-generated, they are self-serving and vague, and they lack an effective enforcement mechanism."[5]

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[1]Dorothy Morgan, "Public Relations and Patient Rights," Dimensions in Health Service 51:11 (November 1974): 11-12.

[2]Edith Lewis, "The Patients' Rights," Nursing Outlook 21:2 (February 1973): 93.

[3]"Hospitals Must Adapt Patient's Bill of Rights or Courts Will Tell Them What it Means, Lawyer Warns," Modern Hospital 120:6 (June 1973): 33-34.

[4]Wing, p. 109.

[5]George Annas, "Voluntary and Regulatory Bills of Patients' Rights," Proceedings: National Symposium on Patients' Rights in Health Care, (Washington, D.C., May 1976): 13.

Other health professionals and lawyers have reacted more moderately, if at all. Curran, an American Lawyer, states that the A.H.A. document only returns to the patient some of the rights the hospitals have previously "stolen" from them. He further describes such a bill as weak, but a basic document upon which to build since it is important to declare publicly that the patient has rights.[1] In short, some see the bill as a mechanism to inform patients of their rights;[2] others see the bill as a reaffirmation of long established principles by health professionals.[3]

In any case, many hospitals in the United States have utilized the bill's advent to inform patients of their rights, and in one case a hospital held a Patients' Rights Workshop intended to make the community aware of hospital services, to provide opportunity to express opinion or complaint, and to advise the potential patient of his rights.[4] Consumers too have utilized the focus on the bill in order to press their rights, as exemplified in New York where eight group practises were co-opted into signing a Patients' Bill of Rights.[5]

Canadian reaction has been similar, varying from enthusiasm to

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[1]William J. Curran, "The Patients' Bill of Rights Becomes Law," New England Journal of Medicine 290 (January 3, 1974): 32-33.

[2]I.D. Snook, "Patients' Rights," Hospitals, J.A.H.A. 48 (April 1, 1974): 177.

[3]"How Well are Patients' Rights Observed?" Hospital Practise 8 (March 1973): 31.

[4]Andre L. Lee and Godfrey Jacobs, "Workshop Airs Patients' Rights," Hospitals, J.A.H.A. 47 (February 16, 1973): 39-43.

[5]"New York Consumers Press Clinics to Sign Patients' Bill of Rights," Hospitals, J.A.H.A. 47 (September 1, 1973): 17.

skepticism. Differences in the Canadian health care system make some of the A.H.A. Bill's points inapplicable, and some would argue that all of these rights are already enshrined in the Federal Bill of Rights, therefore separate patient rights constitute the effect of segregation.[1] Rozovsky, a Canadian lawyer, points out that Canadians already have most of these rights embodied in common law. However, the law "cannot enforce morality, kindness, charity, tenderness or human responsiveness."[2] He states that attempts to legislate these qualities would mislead the public into believing they had acquired enforceable rights, and, therefore, the bill is best seen as a statement of philosophy.[3] A spokesman for the Canadian Medical Association believes, as does the Ontario Medical Association, that the C.M.A. Code of Ethics itself is a patient's bill of rights.[4]

Placing the Patient's Bill of Rights in the hands of the patient is seen to be of questionable value as the patient alone is not in a position to enforce his rights. Some hospitals have employed the services of a patient advocate, patient representative, or a patient ombudsman for the purpose of ensuring patient rights. The role and function of such

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[1]David Jackson, A Brief to the Committee on Rights in Relation to Health Care. Presented by the Saskatchewan Association of Special Home Care, March 4, 1976, p. 11.

[2]L.E. Rozovsky, "A Canadian Patients' Bill of Rights," Dimensions in Health Service 51:10 (December 1974): 9.

[3]Ibid., p. 10.

[4]J.D. Wallace, "Canadian Medicine Has Already Provided the Patient with a Bill of Rights," Canadian Medical Association Journal 113 (November 8, 1975): 888.

workerswill be discussed in chapter 6. Additionally, it has been suggested that outright communication with the public before they enter hospital is a far more effective way to acquaint them with the hospital and their rights.[1] Such communication is part of the consumer's request for information which includes a wide array of information necessary for effective utilization and effective participation.

Right to Be Informed

The right to be informed encompasses the right to information about not only the health care system and patient costs, but also about preventative health education, and information about the individual's own diagnosis and treatment.

Consumers are at a disadvantage in the health care system because they have limited means of learning about the system. The consumer's learning is largely through previous experience, direct or indirect, and those who are informed (the providers) often are oblivious to the needs of their clients to be informed about the "rules of the game." This situation adds to the power of the providers in an organization since they are fully aware of rules and expectations.[2]

Health care providers have been urged to orientate patients to

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[1] A Brief to the Committee on Rights in Relation to Health Care in Saskatchewan. Presented to the Saskatchewan Association of Hospital Administrators. Prepared by an ad hoc committee of the Board of Directors with special assistance from Wayne Fyffe and Murray Martin, November 1975, p. 2. This document will hereafter be designated "Saskatchewan Association of Hospital Administrators' Brief."

[2] Tagliacozzo and Mauksch, pp. 172-173.

the health care environment, to teach them the cultural and technical language, and to assist them in understanding expectations of their role so that they might be able to cooperate in care.[1] One group suggests that such orientation is best done in advance of consumer entrance into the institution by pre-admission literature containing information about patient responsibilities, legislation, rules and regulations; explanation about the function of each category of worker, and direction as to where additional information can be obtained.[2]

Apart from information on the patient's role when in a health care institution, the consumer needs information about health services: where they are, what they are, and how the consumer can gain entry.[3]

> People should enter the health care system in a competent and participatory way, . . . Therefore, it is proposed that all public school curricula include health education. . .teaching should include the role and impact of health professionals, how the system works and how to use it, the rights and responsibilities of a consumer in the health care system, and community resources.[4]

In addition to information and education about the health care system, consumers claim rights to information "about preventative health care including education on nutrition, birth control, drug use,

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[1]Luther Christman, "Assisting the Patient to Learn the Patient's Role," Journal of Nursing Education 6:2 (April 1967): 17-21.

[2]Saskatchewan Association of Hospital Administrators' Brief, p. 10.

[3]Health and Welfare Canada, National Conference on Assistance to the Physician (Ottawa, April 6-8, 1971): 18.

[4]U.S. Department of Health, Education, and Welfare, Proceedings: National Symposium on Patients' Rights in Health Care (Washington, D.C., May 17-18, 1976): 60.

appropriate exercise. . . ."[1] That such information might also be dispensed through public school curricula, has been widely advocated.[2]

> Suggested content might include healthful living, nutrition, body systems, anatomy and physiology, factors affecting health, diseases and populations at risk. . . . In teaching a person to know his/her own body, to be more self-reliant and self-confident, the next generation would be a new kind of patient.[3]

In addition to public school educational activities, consumer health information and education on a broader basis has been a focus of attention. Several recent booklets attempt to inform the consumer on a variety of topics in health,[4] and many more appear on newsstands daily. These information sources generally describe disease trends today, dangers of self-medication and misleading advertising and information to assist the consumer in identifying medical quackery. Information is also provided on selection of medical services, health professionals and their functions, and financial aspects of health coverage.

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[1]"Consumer Rights in Health Care," Canadian Consumer 4:2 (April 1974): 1.

[2]For example, Economic Council of Canada, Health Services Report Prepared by the Health Services Committee for the 1974 Conference (October 1974), p. 3; U.S. Department of Health, Education and Welfare, Proceedings: National Symposium on Patient's Rights in Health Care (Washington, D.C., May 17-18, 1976), p. 60; Cyrus Mayshark, "Heading of Health Care Costs Through Consumer Education," The Journal of School Health 40:6 (June 1970), pp. 280-283; Anne Somers, Health Care in Transition: Directions for the Future (Chicago: Hospital Research and Educational Trust, 1971): 82-83.

[3]U.S. Department of Health, Education and Welfare, p. 60.

[4]See Miriam Tuck, Consumer Health (Dubuque: Wm. C. Brown, 1972); Robert Kime, Health: A Consumer's Dilemma (Belmont, California: Wadsworth Printing Company, Inc., 1970); Kenneth Jones et al. Consumer Health (San Francisco: Canfield Press, 1971).

Right to Health Education

Provision of information to consumers, however necessary, is not sufficient. The consumer has a right to health education which must include: information about health, illness, disability and ways to improve and protect one's health; motivation of consumers to want to change to more healthful practises; and assistance to the consumer in learning the skills to adopt healthy lifestyles.[1] In exercising this right to health education, the consumer begins to exercise responsibility.

Knowles, President of the Rockefeller Foundation, claims that the idea of individual responsibility has been subordinated to individual rights, and that our culture has eroded the idea of individual responsibility.[2] The duty to preserve and protect one's health has been confounded by a credit-minded society (do now, pay later). The critical choice now facing consumers is to change personal bad habits or stop complaining.[3]

In A New Perspective on the Health of Canadians, Lalonde urges greater consumer responsibility for developing and maintaining healthful lifestyles, and further urges health promotion activities aimed at "informing, influencing and assisting" consumers to accept greater responsibility and be more active in matters which affect mental and

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[1]Anne Somers, ed., Promoting Health: Consumer Education and National Policy. A Report of the Task Force on Consumer Education (Germantown, Md: Aspen Systems Corporation, 1976): 75.

[2]John H. Knowles, "The Responsibility of the Individual," Daedalus 106 (Winter 1977): 59-60.

[3]Ibid., pp. 75-78.

physical health. Unfortunately, many people equate such health promotion efforts with encroachment on civil liberties.[1]

Somers, a consultant to the United States Department of Health, Education, and Welfare, advocates that doctors should play a greater role in health education for the public in general, and with their own patients;[2] and others suggest that the hospital should play a central role in health education.[3] Some hospitals are taking a more active role in consumer education as is evident where waiting room education is conducted via videotape presentations.[4] Others are seeking to provide more teaching material for patients by means of brochures.[5] But, at best, education of consumers inside or outside hospitals is spotty, and not clearly recognized as the responsibility of the professional.[6] Too often, relatively useless medications are prescribed in place of the more time-consuming teaching of the patient so that he might

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[1]Anne Somers, "Re-charting National Health Priorities; A New Canadian Perspective," New England Journal of Medicine 291 (August 22, 1974): 415-416.

[2]Anne Somers, "Consumer Health Education: An Idea Whose Time Has Come?" Hospital Progress 56 (February 1975): 10-11.

[3]Dorothy A. Vernstrom, "Hospitals Should Share in a United Effort," Hospitals, J.A.H.A. 30 (July 1, 1956): 41-42; and Marguerite de la Vega, "New Focus on the Hospital as a Health Education Center," Hospitals, J.A.H.A. 40 (July 16, 1966): 78-82.

[4]Mary Heider and Larry A. Early, "Educating Patients in Hospital Waiting Rooms," Nursing Digest 2 (April 1974): 22-24.

[5]For example, Valborg E. Tollesfreid, "We're for Educating Our Patients," American Journal of Nursing 56 (August 1956): 1009.

[6]Anne Eardley, "Health Education by Chance; the Unmet Needs of Patients in Hospitals and After," International Journal of Health Education 18 (1975): 19-25.

understand the pathophysiology of the problem and take appropriate self-care measures.[1]

Information About One's Own Care - Informed Consent

While many health care providers seem able to acknowledge that the patient has a right to know about his own diagnosis and treatment program, others, particularly doctors, have difficulty in conceding this point. Nowhere has this attitude been more apparent than in the controversy surrounding the right of the patient to informed consent.

Hershey and Bushkoff, in a study aimed at determining surgeon attitudes regarding informed consent, found that a high percentage of doctors felt that their patients did not want to be fully informed, and that informing patients might upset and frighten them.[2] That for most patients this perception on the part of the doctor is inaccurate, has been widely expressed. Doctors no longer can be reluctant information givers since the day of the "doctor knows best" feeling of patients is waning with patients requesting status as a partner in health care.[3]

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[1]Wilma Lewis, "Health Behaviour and Quality Assurance," Nursing Clinics of North America 9:2 (June 1974): 362.

[2]Nathan Hershey and Stanley Bushkoff, Informed Consent Study: The Surgeon's Responsibility for Disclosure to Patients (Pittsburgh: Aspen Systems Corporation, 1969): 17. As a note of interest, a survey of physicians by A. Miller, "The Patient's Right to Know the Truth," Canadian Nurse 58:1 (January 1962): 25-29 indicated that seventy percent rarely or never fully disclosed to patients their diagnosis and treatment.

[3]See for example, Lucie Young Kelly, "The Patient's Right to Know," Nursing Outlook 24:1 (January 1976): 26-32; and John A. Mitchell and Charles Cragin, "Informed Consent - A Doctor's Dilemma," AORN Journal 18:4 (October 1973): 810-825.

Etzioni, discussing patients' rights to know, to decide, and to consent, says there is a commonly held assumption that

> . . . to spare the masses the burden of reflection, even of anxiety is often heard from those opposed to fully informing patients. However, it is a highly paternalistic and patronizing view. People are seen as children to be protected by doctors who know better and will make the tough decisions for them.[1]

The right to informed consent relates both to the legal matter of negligence and to battery, where consent to medical treatment is inadequate.[2] On the matter of informed consent, Wing states:

> Basically this requires that the patient be told enough information about the treatment, the alternatives, and the inherent risks of treatment to make an intelligent choice. These are the essential elements of informed consent.[3]

"Half-truths or 'soft answers' today run the risk of either negligent misrepresentation, deceit or even vitiating consent."[4]

Two standards of disclosure are operative in the United States, the professional standard and the full disclosure rule. The professional standard is based upon information medical colleagues would customarily give a patient. Full disclosure involves disclosure of "all material risks incident to the proposed treatment."[5]

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[1]Amitai Etzioni, "The Right to Know, to Decide, to Consent, and to Donate," Nursing Digest 2 (October 1974): 49-50.

[2]Ellen Jacobs, "The Tempest of Informed Consent," in Studies in Canadian Tort Law 1977 (Toronto: Butterworth Co., to be published in Fall 1977). Draft copy, pp. 2-3.

[3]Wing, p. 112.

[4]John G. Fleming, The Law of Torts, 4th ed. (Toronto: The Carswell Company Ltd., 1971): 79.

[5]Jacobs, p. 11.

According to a California Supreme Court decision, the information necessary to the consumer to give consent neither involves a "lengthy polysyllabic discourse" on all complications, nor a "minicourse in medical science," but rather reasonable disclosure[1] to allow the patient to judge the circumstances of his case. Citing the same legal case, at least one doctor finds the legal jargon less than helpful, and concludes that how much to tell a patient remains an enigma.[2] While he concludes that the physician should err on the side of providing more information rather than less information, problems of disclosure persist. In order for the patient to make a truly informed consent, must he know all possible alternatives including "the entire corpus of confusing and conflicting studies surrounding the subject?"[3]

After analyzing a number of Canadian legal cases relating to informed consent and standards of disclosure, Jacobs concludes that the "encompassing standard of disclosure in Canada remains that of the medical profession."[4]

Another pre-requisite of informed consent is that the patient/consumer be in a position to choose freely. Therefore, in addition to knowledge, there must be an "absence from his mind of any feeling of

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[1]Cobbs vs. Grant 8C.3d 229, 502 P.2d1 (1972) as recorded in Wing, p. 116.

[2]Eugene C. Laforet, "The Fiction of Informed Consent," Journal of the American Medical Association 235 (April 12, 1976): 1580.

[3]Ibid., pp. 1581-1582. [4]Jacobs, pp. 12-15.

constraint" so that nothing can interfere with his freedom to decide.[1] The assurance of freedom from constraint is particularly troublesome in health care where insidious pressures on the patient abound.

A central problem in connection with the consumer voluntarily assuming risk is that of establishing a mechanism which justifies the conclusion that a particular risk has been assumed.[2] To this end, health care organizations and health care providers have continued to manufacture consent forms and procedures for obtaining patient consent. But at best, the state of informed consent in health care is neither well understood nor well implemented.

Though the bulk of responsibility in informed consent rests with the physician, this fact does not absolve the hospital and its staff from its responsibility to ensure that informed consent occurs, and that mechanisms exist to monitor its practise. Admitting officers, nurses, and other health care personnel must take greater care in obtaining patients' signatures on consent forms.[3] Reduction of vagueness in treatment consents has been urged nationally in Canada,[4] and legislation to reduce the uncertainties surrounding consent for the mentally disabled, minors and others unable to sign, has been sought.[5]

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[1]Fleming, p. 248. [2]Ibid., p. 244.

[3]Saskatchewan Association of Hospital Administrators' Brief, p. 7. Also see "Informed Consent, the Nurse's Responsibility," AORN Journal 18 (October 1973): 667-668.

[4]Eleanor Le Bourdais, "Reduce Vagueness in Treatment Consents," Dimensions in Health Service 52 (November 1975): 20-23.

[5]Institute of Law Research and Reform, University of Alberta, Report No. 19 Consent of Minors to Health Care, December 1975.

A study conducted in a mental hospital relating to the patient's understanding of consent forms signed on admission attests to a need to re-evaluate procedures for communicating to mentally-ill patients their rights and restrictions, since only one patient in the forty surveyed fully understood what he had signed.[1]

This right to be informed ties in closely with another consumer right, namely, the right to be respected.

Right to Be Respected

The claim for a right to be respected has several dimensions. The consumer is asking for the right of confidentiality of his health records; the right to refuse experimentation, undue prolongation of his life or participation in teaching programs; and the right to refuse treatment and to die with dignity. Overall, the consumer is asking for the right to be respected as the individual who has the major responsibility for his own care.[2]

Thomas Szasz, a controversial psychiatrist, objects to the position the health care consumer is placed in upon entry into the system. The patient is in the position of not knowing his own diagnosis and treatment plan in many instances, not being allowed to see his record, being required to tell all to the physician while the physician withholds information, and other personal indignities. He implores health professionals to safeguard the dignity and self-esteem of the patient.[3] The effects of depriving a

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[1]Alberta Palmer and Julian Wohl, "Voluntary-Admission Forms: Does the Patient Know What He's Signing?" Hospital and Community Psychiatry 23 (August 1972): 38-40.

[2]"Consumer Rights in Health Care," Canadian Consumer 4 (April 1974): 1.

[3]Thomas Szasz, "Illness and Dignity," Nursing Digest 4 (November-December 1974): 130-133.

patient of respect and responsibility for his care, are poignantly stated in the following excerpt:

> I did not want to go to the particular hospital he mentioned; I preferred another. But he did not practise at that hospital. Suddenly I felt fear and panic, as though decisions were being made for me; that I didn't take any part in them. That process, of feeling myself reduced in making decisions about my own fate, became increasingly reinforced and was very destructive psychologically.[1]

While informed consent may have some legal basis of enforcement, the right to respect, including confidentiality, is an ethical rather than a legal right and difficult to enforce. In addition, some intrusion upon one's privacy becomes a necessary part of patienthood, since coordination of staff effort and planning require that some information about the patient be shared.[2]

Renewed concern for confidentiality of health records has surfaced along with increased computer usage. The techniques of computers, laser technology and micro-miniaturization have begun to erode informational privacy.[3] While some beneficial effects for the patient can be achieved, the obligation of users to guard the privacy of the human

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[1]Archie Hanlan, "Notes of a Dying Professor," Nursing Digest 4:3 (May 1974): 37.

[2]Dorothy Smith, "Patienthood and its Threat to Privacy," American Journal of Nursing 69:3 (March 1969): 509.

[3]Arthur R. Miller, "Computers, Data Banks, and Individual Privacy: An Overview," Columbia Human Rights Law Review 4:1 (Winter 1972): 8. For medical usage see Emmanuel Mesel and David Wirtschafter, "Automation of a Patient Medical Profile for Insurance Claims Data: A Possible First Step in Automating Medical Records on a National Scale," The Millbank Memorial Fund Quarterly 54:1 (Winter 1976): 29-46.

beings whose lives are reflected in the dossiers has increased with the increased information available.[1]

Right to the Medical Record

Ownership of the medical/health record has been challenged. Traditionally, the record has belonged to the doctor if the consumer is part of his office practice, or to the health institution where the consumer receives care.

> As the health record is the property of the health care facility, the latter, subject to statutory provisions, may restrict the removal of the record from the hospital premises, determine who may have access to it, and define the kind of information that may be taken from it.[2]

In most states and provinces in North America, patient access to his own record is restricted and can only be obtained by court order.[3] While some would argue that the patient should have unrestricted access to his own record,[4] others are concerned about the problems inherent in such a practice. Given that a medical record can be incomprehensible to the lay reader, one author contends that needless worry and confusion may be caused to the patient by such access. Another problem is that health care providers might be overly cautious in their recording, failing to record

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[1]Miller, p. 10.

[2]Alberta Hospital Association, Safeguarding the Medical Record Interim Revision 1973 (December 1973), p. 10.

[3]Wing, p. 124. For further discussion of ownership of and access to the medical record see Lorne E. Rozovsky, Canadian Hospital Law (Toronto: Canadian Hospital Association, 1974): 65-66; Alta Hosp Act, R.S.A. 1970; c.174 as amended; Larry Wagar, "The Medical Record and Its Legal Effect" Faculty of Law, University of Alberta, Edmonton, April 1976 (typewritten).

[4]See for example, Budd N. Shenkin and David C. Warren, "Giving the Patient His Medical Record: A Proposal to Improve the System," New England Journal of Medicine 289 (Sept. 27, 1973): 688-692; F.A. Murray, "Patients as Record Holders," Health and Social Service Journal (July 27, 1974): 1675.

certain possible diagnoses or observed symptoms, to the patient's inevitable detriment.[1]

Almost all would agree, however, that the time of choice in the matter may be ending, particularly in the United States where state legislatures have passed laws allowing patients full or partial access to their records.[2] Rozovsky and Marshall have urged health care institutions in Canada to establish firm guidelines for the use of staff in divulging information regarding medical records, because of legal uncertainties in this area.[3] The Alberta Hospital Association has had a committee which has established some beginning guidelines of this nature, but a need for constant attention to this task is evident.[4]

Information contained in the medical record must be treated as private and confidential by persons having access to the patient's record.[5] Therefore, the patient's right to confidentiality of his record or information from his record is the rule except under three

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[1]Helen Creighton, "Patient's Access to His Own Medical Record," Supervisor Nurse 4 (May 1973): 12-13, 16.

[2]Kelly, p. 30; U.S. Department of Health, Education and Welfare, Proceedings, p. 32.

[3]Lorne E. Rozovsky and C. Marshall, "Confidentiality of Medical Records," Dimensions in Health Service 51 (July 1974): 10-11, 12.

[4]Alberta Hospital Association, Safeguarding the Medical Record.

[5]R.S.A. 1970, c. 174; Wagar, pp. 18-21.

circumstances, namely, "disclosure under a court order, disclosure when required by provincial statute, and disclosure when required or justified as a matter of public policy."[1] Information on the patient's record is not protected, i.e., it is subject to disclosure in court.

> With the exception of Quebec, even the record of communications between the patient and the physician must be divulged at the order of a court. . . . The only communication which the English Common Law recognizes as 'privileged' is a communication between a client and his lawyer.[2]

The second exception to the confidentiality rule occurs when provincial statute requires disclosure to the Workmen's Compensation Board, the Hospital Commission, Blue Cross or other bodies. Concern for public welfare becomes the basis of justification for the third type of disclosure, as exemplified in communicable disease control practices.[3]

Right to Refuse

Consumer rights to refuse include the right to refuse to participate in research, teaching, or treatment. Following World War II, the question

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[1]Wagar, p. 21; Rozovsky, p. 67.

[2]Rozovsky, pp. 22-26.

[3]Wagar, pp. 22-26.

of the law of consent in relation to human experimentation arose when the extent of Nazi doctors' experiments on prisoners of war became known. Three American judges wrote what became known as the Nurenberg Code in 1947,[1] which was adopted by the World Medical Association Declaration of Helsinki in 1964.[2] The Code includes basic principles and guidelines for clinical research and non-therapeutic clinical research.

Other groups have since joined to establish research ethics such as the American Psychological Association in 1953, the Surgeon-General Department (U.S.A.) in 1966,[3] the American Nurses' Association in 1968,[4] and the Canadian Nurses' Association in 1972.[5] All would agree that while research in new ways of care is necessary, it must be voluntary.

Particular concerns of the consumer in regards to human experimentation situations are those of invasion of privacy, loss of dignity or autonomy, mental or physical discomfort, and the risk of physical or emotional injury. The consumer needs to be free to decide regarding the time, circumstances, and extent of his involvement once disclosure of the

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[1]Annas, p. 15.

[2]"Declaration of Helsinki," The New England Journal of Medicine 271 (August 27, 1964): 473-4.

[3]Jeanne Saylor Berthold, "Advancement of Science and Technology While Maintaining Human Rights and Values," Nursing Research 18:6 (November-December 1969): 516.

[4]American Nurses' Association, "The Nurse in Research: A.N.A. Guidelines on Ethical Values," Nursing Research 17:2 (March-April 1968): 104-107.

[5]Canadian Nurses' Association, "Ethics of Nursing Research," Canadian Nurse 68:10 (September 1972): 23-25.

right, and even fewer actually inform the patient that he has this right.

Right to Die

"Death has become the ultimate form of consumer resistance."[1] The right to refuse treatment and to die with dignity has been a matter of widespread attention in the past year. Fox notes that recent medico-legal decisions have far-reaching cultural implications affecting "society's conceptions about life, death, the body, individuality and humanity."[2] The Karen-Ann Quinlan case is one of these decisions in which the right to be removed from the life-support system was requested, refused by the Superior Court of New Jersey, and subsequently appealed and granted by the Supreme Court of New Jersey, March 31, 1976.[3] The passage of California's Natural Death Act, effective January 1, 1977, allowing patients the right to refuse life-support treatment is also a recent decision with far-reaching consequences. The act allows a patient to write a directive to a physician asking that his life not be "artificially prolonged." A fifty six year old kidney patient was allowed to die recently as a result of this provision amidst a swarm of controversy as to whether he was really covered by the act.[5]

Illich, theologian and philosopher critic, describes the medicali-

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[1]Ivan Illich, Medical Nemesis (London: Calder and Boyers, 1975), p. 149

[2]Fox, pp. 12-13.

[3]Stanley Joel Reiser, "Therapeutic Choice and Moral Doubt in a Technological Age," Daedalus 106 (Winter 1977): 49-50; also see Joseph M. Healey, "The Quinland Case and the Mass Media," American Journal of Public Health 66 (March 1976): 275-6.

[4]Natural Death Act, State of California, 1976, c. 3.9.

[5]Edmonton Journal, April 7, 1977, p. 35.

zation of death as a product of a highly industrialized society. Whereas formerly man experienced death as a 'natural death,' death now is that point at which the human body refuses any further input of treatment. He likens medical practice as a game in which the chief function of the physician is as umpire. The rules of the game forbid leaving the game and dying in a fashion unspecified by the umpire.[1] The New Jersey Superior Court, in fact, supported this notion by stating that decisions about medical care were the responsibility of the physician given by Society, in regards to the nature, extent, and duration of care.[2] The Supreme Court's overriding decision in this case was based upon the fact that "no interest of the State could compel Karen to endure the unendurable. . . ."[3]

Reiser, Professor of Medicine at Harvard, traces the extent of medical aggression on nature back to the Hippocritic writings in which the physician is urged to use restraint in a fairly well understood technology to the present complexities of medicine where uncertainty increases.[4] In an extensive study regarding factors influencing physician decisions to treat critically ill patients, Crane concludes that more precise medical guidelines are necessary in order for doctors to make these difficult decisions.[5] While medical guidelines may be of some benefit, the days of unilateral decision-making are over, and the time for consumers to assume a greater role in examining moral principles to guide medical decisions has arrived. The masses are ready to share the burden of reflection and

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[1]Illich, pp. 147-149.

[2]Reiser, p. 50.

[3]Ibid.

[4]Ibid., pp. 51-52

[5]Diane Crane, "Decisions to Treat Critically Ill Patients: A Comparison of Social Versus Medical Considerations," The Millbank Memorial Quarterly (Winter 1974): 29-31.

anxiety, and the consumer wants the right to die with dignity.

Rights and the Mentally Ill

One of the most difficult areas of health care in which to assure the exercise of patient rights is that of the care and treatment of the mentally ill. The dilemma of civil liberties versus community and individual safety, is readily apparent in the processes of commitment and detention of the mentally ill.[1] The system of commitment to a mental facility rests largely on medical opinion, and Wing maintains that to date any court orders have been little more than rubber stamps for the physician's decision.[2]

Draper, an Alberta Lawyer, questions the criteria for confinement in the Mental Health Act of Alberta in which doctors are given substantial power.

> . . . it is rather surprising that determining what constitutes mental disorder has been so completely left to the discretion of individual doctors. Many of the doctors signing admission certificates have little psychiatric training. . . .[3]

In comparing the confinement process of criminals to the confinement process of the mentally ill, Draper concludes that legal procedures for involuntary confinement are in need of change in favor of the mentally ill. A person charged with a criminal offense has a right to be heard by an impartial tribunal, whereas the person alleged to be mentally disordered is examined by two doctors who assume the role of

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[1]L.W. McKerrow, "The Dilemma of Psychiatric Hospitals: Patient Rights vs. Public Safety," Hospital Administration in Canada 18 (March 1976): 67-68.

[2]Wing, p. 31.

[3]Gary Draper, "Due Process and Confinement for Mental Disorder," Alberta Law Review 14 (1976): 274.

prosecutor, judge, and jury. Draper further points out that such a situation under the Criminal Code would be analgous to two police officers interrogating the accused and then sentencing him.[1]

> Society has elected to leave the issue almost entirely to the discretion of the medical profession. . . . Physicians have a tendency to see the mentally disordered individual as sick and in need of treatment, discarding the person's freedom as relatively unimportant.[2]

Perhaps appropriately, because the vulnerability to abuse is so great, some of the first legal issues specifying a right to treatment and a right to quality of care originated in psychiatric care facilities. One of the most significant cases was the case of Wyatt v. Aderholdt, 503 F.2d 1305 (5th Cir 1974) which was formerly known as Wyatt v. Stickney in Alabama.[3] This case evidenced the potentially important role of judges in extending individual rights to patients since the court approved constitutional standards in patient rights, specifying upwards of twenty one rights to specific services and opportunities for those committed. In addition, minimum standards of staff-patient ratios were defined, and the Commission of Mental Health was given a time frame within which to make necessary changes.[4]

That rights of the mentally ill continue to be a concern is evidenced in the number of complaints reaching ombudsman offices since their instigation.[5]

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[1]Ibid., p. 278.

[2]Ibid., pp. 287-288.

[3]Wing, p. 49.

[4]Charles Prigmore and Paul R. Davis, "Wyatt v. Stickney: Rights of the Committed," Nursing Digest (Summer 1974): 70-77.

[5]For example, see Province of Alberta, Report of the Ombudsman, Annual Reports 1967 to 1974.

Right to Participate in Decision-Making

The right to participate involves both a consumer right to participate with health care providers involved in the consumer's direct care, and the right to participate through consumer representation in planning and evaluating the health care system.[1]

Even when the patient is unable to carry his full load, partnership is advocated in the healing process.[2] The responsibility of the health care provider is to aid and guide patients in their decision-making in such a way as to not prejudice their decision-making.[3] Kramer has advocated patient involvement in nursing care plans as a way to allow the patient to participate and to give "patient power."[4] A Health Maintenance Organization in Philadelphia has implemented joint staff-patient formulation of the patient's health care plan which emphasizes shared responsibility.[5] Patient participation in the planning of his own care often results in the patient assuming greater responsibility for the outcome or effect of that care, and in this way,

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[1]"Consumer Rights in Health Care," Canadian Consumer 4:2 (April 1974): 1.

[2]Gertrud B. Ujhely, "The Patient as Equal Partner," Canadian Nurse 69:6 (June 1973): 23.

[3]Christian Hovde, "The Need for Participation," Occupational Health Nursing 18:11 (November 1970): 11.

[4]Marlene Kramer, "Standard 4 Nursing Care Plans. . . Power to the Patient," Journal of Nursing Administration (September-October 1972): 29-34.

[5]Charles G. Hertz, Joseph W. Bernheim, and Thomas N. Perloff, "Patient Participation in a Problem-Oriented System: A Health Care Plan," Medical Care 14:1 (January 1976): 77-78.

partnership aids recovery.[1]

Patient participation in psychiatric care facilities has been a particularly useful venture as it encourages patients to assume an active stance[2] which is more consistent with expected "sick role" behavior in mental illness.[3]

Patients' evaluation of their own care is an important dimension of patient participation.

> A very important source of information, but one frequently not used to full advantage, is the consumer (the patient) and his relatives. One can perhaps learn more from their dissatisfaction than from their satisfaction.[4]

Patients are qualified to judge care, and mechanisms for their input into the evaluation of care must be established.[5] Caution must be exercised, however, in the mechanisms used to allow the consumer this right. In some instances, consumers may be afraid to comment negatively on their care for fear of reprisal,[6] or they may not be encouraged to

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[1]Phyllis Tyron, "Patient Participation vs. Patient Passivity," Nursing Forum 2:2 (1963): 56-57.

[2]A.D. Fang, "These Patients are Assisting with Their Own Ward Management," Hospital and Community Psychiatry 17:6 (July 1966): 16-19; see also, Virginia L. Fanning et al. "Patient Involvement in Planning Own Care: Staff and Patient Attitudes," Journal of Psychiatric Nursing 10:1 (January-February 1972): 5-8.

[3]Segall, pp. 163-164.

[4]Karl Evang, "The Politics of Developing a National Health Policy," International Journal of Health Services 3:3 (1973): 336

[5]Richard Wessler, "Patient Opinions: What Do They Really Mean?" Hospital Progress 49:7 (July 1968): 53.

[6]Virginia Nehring and Barbara Geach, "Patients' Evaluation of Their Care - Why They Don't Complain," Nursing Outlook 21:5 (May 1973): 317.

express their real concerns, instead expressing only peripheral and symptomatic complaints.[1]

Right to Participate in Planning and Evaluation of Health Services

Consumer participation in "planning and evaluating the system of health services, the types and qualities of service and the conditions under which health services are delivered"[2] raises several immediate questions. What type of participation? Why should consumers be involved? Who is the consumer representative? How can consumers be used effectively? These questions will be addressed in discussing the concept of consumer participation.

What type of participation?

Consumer participation means many different things to different people. To some it may be a simple advisory process, to others a creative process; to some a feedback process, and to others a dynamic process of re-definition of roles and responsibilities.[3]

A variety of forms of consumer participation are evident in the consumer involvement in planning and evaluation of health services to date. In some situations, consumers have complete administrative control of the health service, including the right to

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[1]Donald Houts, "The Patient Has Something to Say," Hospitals, J.A.H.A. 32:23 (December 16, 1958): 38-40.

[2]"Consumer Rights in Health Care," Canadian Consumer 4:2 (April 1974): 1.

[3]Thelma McCormick, "Citizen Participation," in Report of the Special Study regarding the Medical Profession in Ontario, Edward A. Pickering, Project Director. (Toronto: Ontario Medical Association, 1973): 3.

hire and fire and to determine the content and method of delivery of the services. In other situations, consumers function as an advisory body, or participation is in the form of opinion exchange only.[1]

Feingold describes types of consumer participation in planning and evaluation of health services employing a ladder concept. The first rung is informing the consumer (a one-way flow of communication with no feedback or negotiation); the second rung is consultation (wherein attempts are made to ascertain the citizen's views but with no assurances that these views will be respected); and the third rung is partnership (wherein power is redistributed by negotiation between consumers and power-holders). The final two rungs consist of delegated power (wherein citizens hold dominant authority) and citizen control (wherein the consumer is in full charge of a program's policies and management).[2]

While the first rung, the information-giving to consumers, would appear to be a commonly practised type of involvement, this has not been the case, and many times the consumer is uninformed about health services and issues because the information-holders are not eager to share.[3]

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[1]Ann T. Slavinsky and Vivian Romanoff, "Consumer Participation," Journal of Nursing Administration 2:3 (May-June 1972): 14-18.

[2]Eugene Feingold, "Citizen Participation: A Review of the Issues," in The Citizenry and the Hospital, pp. 12-13. (Durham, N.C.: Duke University, 1974). See also, Rudolf Klein, Notes Towards a Theory of Patient Involvement. A Commissioned Paper to the Community Health Centre Project. (Toronto: Canadian Public Health Association): 2.

[3]Robert Pecarchik, Edmund Ricci, and Bardin Nelson, "Potential Contributions of Consumers to an Integrated Health Care System," Public Health Reports 91:1 (January-February 1976): 73.

The consultation process occurs occasionally in planning and evaluation of health services. It may vary from attempts to solicit opinions on the planning of a new health care facility[1] to general surveys of consumer satisfaction with health care[2] to surveys of consumer health care wants and needs.[3] Some would seriously question whether the consumer is able to identify his health care wants and needs.[4]

The partnership type of consumer participation is one many health organizations might idealize but seldom achieve since it necessitates negotiation between provider and consumer. Such a process calls for the sharing of power by the health care professional, most of whom are reluctant or ill-prepared to face such a situation.[5]

> Community participation implies that consumers will share in decision-making. They will actually have some of the power. This concept is threatening to some health pro-

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[1]Keith Eric Johnson, "Consumer Involvement in Community Planning," Hospitals, J.A.H.A. 47:3 (February 1, 1973): 59-64.

[2]Lawrence S. Linn, "Factors Associated with Patient Evaluation of Health Care," The Millbank Memorial Fund Quarterly 53:4 (Fall 1975): 531-548. See also, John E. Ware and Mary Snyder, "Dimensions of Patient Attitudes Regarding Doctors and Medical Care Settings," Medical Care 13:8 (August 1975): 669-682.

[3]Stanley Greenhill, "What Does the Public Want of Health Services?" Canadian Journal of Public Health 63:2 (March-April 1972): 108-112; and Wm. C. Richardson and Duncan Neuhauser, "First Question in Health Planning: Does the Public Know What It Wants or Not?" Modern Hospital (May 1968): 115-117.

[4]Richardson and Neuhauser, p. 172.

[5]M. Alfred Haynes, "Professionals and the Community Confront Change," American Journal of Public Health 60:3 (March 1970): 519.

> fessionals. This is especially so in the case of the physician who, under some circumstances must of necessity be authoritarian. . . .[1]

The latter two types of consumer participation, delegated power and citizen control, are two types of participation rarely achieved without difficulty. Some have questioned whether there can be meaningful participation without control, since other types are often initiated as, or degenerate into, tokenism.[2] Jonas states that consumer control is an illusion since true control lies in control of capital structure; expense budgets; and quality and quantity of staff, none of which are subject to consumer control.[3] Ginzberg supports this thinking and sees consumer control of men, money, and management as difficult except in select instances.[4] Nader suggests that consumers should be on quality control committees such as tissue review committees in hospital, and thereby have greater control.[5]

A slightly different role for consumer participants is a role for consumers as provocative agents between the health care professionals on the one hand, and health care planners and administrators on the

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[1]Ibid., p. 521.

[2]Pedro Ruiz, "Consumer Participation in Mental Health Programs," Hospital and Community Psychiatry 24:1 (January 1973): 38.

[3]Steven Jonas, "A Theoretical Approach to the Question of Community Control of Health Services Facilities," American Journal of Public Health 61:5 (May 1971): 918.

[4]Eli Ginzberg, "Health Services, Power Centers, and Decision-making Mechanisms," Daedalus 106:1 (Winter 1977): 208.

[5]"Nader Group Plans Manual for Hospital Users," Modern Hospital 120:8 (June 1973): 23-27.

other. Consumers are in a position to publicly provoke issues which may allow the professionals and the planners to get together in the implementation of these issues.[1]

One writer suggests that the consumer be removed from planning and evaluative bodies. Instead, the consumer's personal income ought to be increased so that he has the potential to use the various health facilities dependent upon his decision as to which services best serve his needs.[2] In this manner (a free-market system) he would be able to influence the system.

It is evident, then, that the type of consumer participation proposed or in operation is variable in type and net result. In the United States, the Economic Opportunity Act of 1964 gave considerable impetus to the concept of maximum feasible participation by consumers.[3] However, as has frequently been evidenced, little direction was given as to how to effect such participation, and to date few instances of the truly effective consumer in health planning and evaluation are evident.[4] In Canada the situation is not significantly different.

Since 1970, numerous Canadian reports on health services have addressed the issue of consumer participation in health planning.

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[1]Pecarchick, p. 74.

[2]G.L. Maddox and Eugene A. Stead, "The Professional and Citizen Participation," in The Citizenry and the Hospital, p. 82.

[3]G.A. Silver, "Community Participation and Health Resource Allocation," International Journal of Health Services 3:2 (Spring 1973): 119.

[4]Maddox and Stead, p. 81.

Federal reports previous to 1970, particularly the Royal Commission on Health Services and the Task Force Reports on the Cost of Health Services, pay no real attention to consumer representation on the various boards they propose. The Community Health Centre in Canada report, however, speaks of effective participation in relation to health centre boards and area boards. Area-wide representation of consumers is seen as essential, but no guidance is provided to effect such representation and participation.[1]

Provincially, several reports recommend consumer involvement in decision-making in the health care system with varying degrees of guidance regarding implementation. The Castonguay report in Quebec was one of the first to prescribe broad consumer representation both at a regional level and at a local level, with non-professionals constituting a majority on boards.[2] Foulkes, in British Columbia, also advocated local and regional boards composed of consumer, professional and worker. He states that the public must feel that it can participate in the development and implementation of a new system, but also expresses concern that consumer participation be at the 'right' level.[3]

Manitoba's White Paper recommends a majority of user represen-

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[1]The Community Health Centre in Canada, by John E.F. Hastings, Chairman (Ottawa: Information Canada, 1972): 50-51.

[2]Claude Castonguay, "Reorganization of Health and Social Services in Quebec," Canadian Journal of Public Health 62:3 (May-June 1971): 192-198.

[3]Richard G. Foulkes, Health Security for British Columbians 1:3 (Province of British Columbia, December 1973): 1-3.

tatives on community health centre boards, and envisions district boards of predominantly lay representatives from a variety of community groups who are "suitably informed" for their important responsibilities.[1] The McLeod Report of Saskatchewan discusses consumer participation broadly, recommending consumer representation on advisory and planning bodies and suggests that such representation should be of three equal parts: physicians, allied health professionals, and laymen. The lay representation is to consist of people "already informed about and capable of being informed about the problems of health care."[2]

The Health Planning Task Force of Ontario recommended District Health Councils with authority for planning and policy in the geographic area. Each Council was to consist of ten impartial members appointed from five nominees submitted by representative community groups or individuals in the district, and five representatives from municipal governments in the district.[3] In most of the reports, where it is recommended that lay representation dominate boards, health professionals are to function on advisory committees to these boards.

Progress to date in implementing the ideas on consumer participation contained in these reports, has been varied. Ontario has

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[1] White Paper on Health Policy, Cabinet Committee on Health Education and Social Policy. S.A. Miller, Chairman (Government of Manitoba, July 1972): 39-40.

[2] J.T. McLeod, Consumer Participation, Regulation of the Professions, and Decentralization of Health Services. A Report submitted to the Minister of Health, Saskatchewan (Regina, Sask.: August 1973): 49.

[3] Report of the Health Planning Task Force, J.F. Mustard, Chairman (Ontario Ministry of Health, January 1974): 27.

established fifteen advisory health councils at a district level which are just beginning to learn and re-define their goals. Quebec and British Columbia began experiments with participation but with somewhat disappointing outcomes. The result has been an apparent decline in commitment on the part of both provincial governments to the idea of citizen participation due to the public's apathy.[1] Hepworth suggests that rather than a state of apathy, the problem is one of a state of ignorance about the role and function of community agencies, public and private.[2]

Probably the most salient lesson to be gleaned from experiments in consumer participation to date is that such involvement must be tailored to the needs and goals of the institution or organization. There is no one "best format or magical formula" for consumer input.[3] Care must be taken to define the role and authority of the consumers[4] whether on boards, advisory committees, standing committees, ad hoc task forces, or in whatever form the consumer input assumes.

Why Should Consumers Be Involved?

The question of why consumers should be involved in health care

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[1]H. Philip Hepworth, Community Multi-Service Centres (Ottawa: The Canadian Council on Social Development, 1976): 101.

[2]Ibid., p. 102.

[3]Jay Okun Yedvab, "Consumer's Role in Defining Goals, Structures and Services," Hospital Progress 55 (April 1974): 59-60. Also see Eugene Feingold, p. 15.

[4]James G. Haughton, Citizen Involvement in Health Affairs. A Commissioned Paper to the Community Health Centre Project. (Toronto: Canadian Public Health Association): 5.

planning and evaluation relates to the choice of type of consumer participation just discussed. Those who limit consumer participation to an information-giving process often do so with the rationale that informed consumers will better understand the true picture and readjust to the facts of limited resources.[1]

For those who advocate greater involvement than simply receiving information, the reasons include some of the following: citizen participation provides opportunity for consumers to express their needs, to identify weaknesses in the present system, to limit the bureaucratic nature of organizations, to make public and private services more responsive to human needs, to act as a watchdog on organizational practices, and to watch over standards of service.[2] Others stress the basic human needs consumer participation could supply, in that participation contributes to human dignity, a sense of meaning, and a sense of control.[3] Government's need for more and better input and the facilitation of the levelling of complaints are additional reasons given for consumer participation.[4]

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[1]Anita Germaine, "Expectations and Realities," Hospital Administration in Canada 16:12 (December 1974) 22. A similar purpose of information to the consumer is conveyed in the Task Force on the Cost of Health Services in Canada (Ottawa: Information Canada, 1970) when the need for the consumer to understand and cooperate with the total health services system is discussed. Vol I, p. 7.

[2]Hepworth, p. 103.

[3]"Why Involve Consumers?" American Journal of Nursing: 11 (November 1972): 2009.

[4]McLeod, p. 37.

The false expectations for consumer participation evolved by some advocates have been credited with much of the present problem of consumer participation. Focus on the poor as participants, in hopes that participation might overcome feelings of alientation and rejection, or overcome the hostility of the poor to existing institutions, or allow the poor to act as a pressure group, have only increased the problems of effective consumer participation.[1]

Who is the Consumer Representative?

How to select representatives from amongst consumers is a key question. In the case of a local facility, part of the selection decision rests upon how the community is conceptualized. For example, does the facility serve a certain geographical area, a vocal minority, or an elitist group?[2] Very often stress has been placed upon involving only the "right" kind of people, meaning either those with access to financial resources, education, or both.[3] In some cases an election process has occurred from amongst a group of area-users to produce the

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[1]Michael Lipsky and Morris Lounds, "Citizen Participation and Health Care: Problems of Government Induced Participation," Journal of Health Policy and Law 1:1 (Spring 1976): 93. See also, Arnold I. Kisch, "Adapting Health Manpower to Consumer Needs and Cultural Expectations," Inquiry 8:3 (September 1971): 40.

[2]David C. Regester, "Community Mental Health - For Whose Community?" American Journal of Public Health 64:9 (September 1974): 893. See also Haynes, p. 521.

[3]See for example, V. Willie, "A Success Story of Community Action," Nursing Outlook 9:1 (January 1961): 19-21.

consumer representatives.[1] In many instances, consumer representatives are selected from citizen organizations or groups.[2]

Invariably, consumer selection remains one of the most difficult problems of consumer participation. Levi contends that where public monies are being spent on public programs, consumers should be represented only by their elected officials. Representatives of private groups or other organizations have the authority to speak only for their membership, and not more.[3] Few would agree with these limited criteria for selection.

How Can Consumers Be Used Effectively?

> . . [T]he presence of consumer representatives on the management board, even though these representatives account for 51 percent of the membership, does not in itself guarantee meaningful consumer participation in decision-making and planning. The most salient factor in meaningful participation by the consumer membership is its preparedness.[4]

Though some have argued that educating the consumer negates his ability to truly represent consumers in that he then becomes indoctrinated by the system, most organizations involving consumers appear to have established some orientation and education programs, however minimal.

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[1]See for example, J. Potuznik and M. Blanks, "Elected Residents Serve on Board," Hospitals, J.A.H.A. 47:12 (June 16, 1973): 60-65.

[2]See for example, Joann G. Graves, "Involvement of Consumers," Hospitals, J.A.H.A. 44:19 (October 1, 1970): 46-50.

[3]Julian H. Levi, "Who Can Speak for the Citizen?" in The Citizenry and the Hospital, p. 101.

[4]Pecarchik, p. 75.

[5]I.e., he converges to the predominant norms of the system which are likely to be bureaucratic and/or professionally orientated.

A study monitoring the effects of a seven-member consumer evaluation team is described by Hessler and Walters. Effects of this type of consumer participation were found to be valuable to all parties, though somewhat constrained by education levels.[1] Fuchs contends that the public "need to know", in order to be involved in difficult decisions facing health care providers. In order to educate consumers he attempts to define problems and present facts to enable consumers to understand individual and social choices.[2] While not all health providers may see the issues as clearly as Fuchs, professionals have a role to play in educating and assisting consumers in order that they might share in decision-making.[3]

Additional Problems Surrounding Consumer Participation

Possibly the greatest difficulty surrounding implementation of consumer participation relates to a lack of interest by many consumers in being involved in health care planning and evaluation. This lack of interest may relate to the growing technical complexity of the medical system, skepticism about influencing costs, or lack of health as an immediate concern.[4] Other reasons for lack of interest may be that:

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[1]Richard Hessler and Michael J. Walters, "Consumer Evaluation of Health Services: Implications for Methodology and Health Care Policy," Medical Care 8 (August 1975): 683-693.

[2]Victor R. Fuchs, Who Shall Live? (New York: Basic Books Inc., Publishers, 1974).

[3]Samuel Wolfe, "Consumerism and Health Care," Public Administration Review 31 (September-October 1971): 535.

[4]Rudulf Klein, Notes Towards a Theory of Patient Involvement. A Commissioned Paper to the Community Health Centre Project. (Toronto: Canadian Public Health Association): 10-11.

1) health services are not used routinely; 2) individual health problems are not attributed to present health institutions; 3) health care as a community problem has not been generally accepted; 4) discrepancies in care are not highly visible; and 5) the perceived legitimacy of the medical profession negates the need to be involved.[1]

Professional resistence occurs as well, particularly when consumers are represented on health professional regulatory boards.

> Opponents of public membership claim that nonprofessionals cannot understand board activities since they do not understand or have the knowledge of practise needed to serve on a board. Others assert that consumers will only interfere with normal business activities of boards. Still others ask who the public represent and question their purpose in seeking membership on health professional boards.[2]

Other complications arise from the "lack of homogeneity of health service consumers as a group," resulting in problems of selection.[3] In addition, training of the consumer is a time-consuming process, and some argue that "a great deal of time is spent by inexperienced people learning the hard way what experts could have told them."[4]

Right to Equal Access to Health Care

The right to equal access to health care regardless of the individual's economic status, sex, age, creed, ethnic origin and

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[1]Lipsky and Lounds, pp. 90-91.

[2]Dale B. Christensen and Albert I. Wertheimer, "Consumer Action in Health Care," Public Health Reports 91 (September-October 1976): 406-411.

[3]Klein, p. 10.

[4]McCormick, pp. 30-31.

location, embodies the right of access to adequately qualified health personnel, the right to a second medical opinion, and the right to prompt treatment in emergencies.[1]

Equal access implies that all persons should have a chance to a fair portion of the resources available for health care.[2] But very often, this right involves confusion between need and demand.[3] Several policy planners reflect concern about the open-ended nature of the right to health care as equated with the notion of a right to equal access to health care. Some suggest that governments need to buffer themselves against excessive demands by clarifying that it be the "best possible" health care,[4] or alternately, that health services must be rationed.[5]

As early as 1929, the statement was made that

> . . . people everywhere have been educated as to what constitutes good medical and nursing care, and are demanding it for themselves and their children.[6]

As technology has increased, demands have multiplied, aided by television which has produced what some have labelled the "Marcus Welby syndrome" of growing public expectation.[7] In analyzing equality and rights in care, Charles Fried points out that medical advances have created a situation which poses acute analytical and social problems in regards

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[1]"Consumer Rights in Health Care," Canadian Consumer 4 (April 1974): 1.

[2]Callahan, p. 31. [3]Detwiler, p. 16. [4]Ibid.

[5]Lloyd Detwiler, "National Health Insurance: Can We Learn from Canada?" Hospital Progress 55 (September 1974): 80.

[6]Anne L. Hansen, "The Nurse in the Community," American Journal of Nursing 29 (March 1929): 263.

[7]Ivan Bennett, "Technology as a Shaping Force," Daedalus 106 (Winter 1977): 132.

to the notion of a right to health care. Therefore, it is important to distinguish between a right to health care and a right to health, and perhaps a right to a certain standard of health care.[1]

> If we commit ourselves to the notion that there is a right to whatever health care might be available, we become involved in a difficult situation whereby the overall national expenditure on health will reach absurd proportions - absurd in the sense that far more is devoted to health at the expense of other important social goals than the population in general wants.[2]

On the other hand, if equality is the prime goal, then the quality of health care for all must be lowered in order to maintain a reasonable financial limit. Such a decision would inevitably require that much research be foregone, since its benefits would not apply to all. Fried concludes, then, that

> Apart from a rather general commitment to equality and, indeed, to state control of the allocation and distribution of resources, to insist on the right to health care when that means a right to equal access is an anomaly. For as long as our society considers that inequalities of wealth and income are morally acceptable. . . it is anomalous to carve out a sector like health care and say that <u>there</u> equality must reign.[3]

That certain groups and areas are underserviced in relation to health services is impossible to dispute. The need to improve access to health services to the poor[4] and to racial minorities[5] is an

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[1]Charles Fried, "An Analysis of 'Equality' and 'Rights' in Medical Care," <u>Hospital Progress</u> 57:2 (February 1976): 44-49.

[2]Ibid., p. 46. [3]Ibid., p. 47.

[4]Roger A. Reynolds, "Improving Access to Health Care Among the Poor - The Neighbourhood Health Centre Experience," <u>The Millbank Memorial Fund Quarterly</u> 54 (Winter 1976): 47-82.

[5]Louise M. Okada and Gerald Sparer, "Access to the Usual Source of Care by Race and Income in Ten Urban Areas," <u>Journal of Community Health</u> (Spring 1976): 163-164.

accepted premise in North American health care delivery, as is the need to improve the balance amongst primary, secondary, and tertiary care.[1]

Wildavsky suggests that there is some confusion rampant in our equation of medical care with health. Because of this confusion, goal displacement occurs which equates health to equal access to medicine. But since better access does not equal better health, a double displacement occurs when, because of uncertainties surrounding health, "caring" becomes substituted for "doctoring" so that we have care instead of health, and access instead of caring. In this way equality, not health, becomes the issue.[2] "One can always assert that even if the results of medical care are illusory, the poor are entitled to their share."[3]

The problem of maldistribution of physicians has been tackled with limited success. Schemes to subsidize medical students in return for commitment to work in underserviced areas,[4] or schemes to provide bonus payments to retain physicians in these less desirable areas,[5] have met with only partial success. Wildavsky suggests that any scheme to oblige people to stay in certain areas will be fraught by efforts of

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[1]Roger M. Battisella, "The Right to Adequate Care," Nursing Digest 4 (January-February 1976): 12-18.

[2]Aaron Wildavsky, "Doing Better and Feeling Worse: The Political Pathology of Health Policy," Daedalus 106 (Winter 1977): 105-107.

[3]Ibid., p. 107.

[4]H.R. Mason, "Effectiveness of Student Aid Programs Tied to a Service Area," Journal of Medical Education 46 (July 1971), p. 583.

[5]W.J. Copeman, "177 of 203 Doctors Stay in Underserviced Areas," Ontario Medical Review 40 (December 1973): 774-775.

these practitioners to escape.[1] Somewhat humorously Wildavsky claims a misnomer of the problem. He reasons that for doctors to be maldistributed, they would have to be where people are not, yet they're accused of staying to the main population areas. Therefore, "it is the potential patients who are maldistributed."[2]

In any event, problems of underserviced areas are likely to persist, though regionalization efforts and use of para-medical personnel hold some promise for increasing services to these areas.

Consumer concern for access to adequately qualified health personnel is of long standing. As discussed in chapter 4, the state delegates the authority of licensing to the professional body for the single purpose of guaranteeing standards of quality and service.[3] The consumer has imperfect knowledge of professional quality[4] and, therefore, must rely upon professionally-imposed standards to assure him that he is being served by adequately qualified personnel.

Apart from unilateral professional association assurances, mechanisms such as accreditation can also represent to the consumer some assurance of quality. One such example is the Canadian Council on Accreditation made up of five sponsoring groups (the Canadian Medical Association, the Canadian Hospital Association, the Royal College of

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[1]Wildavsky, p. 109. [2]Ibid.

[3]McLeod, pp. 65-73.

[4]George Tsalikis, The Patients Freedom of Choice and Community Health Centres. A Commissioned Paper to the Community Health Centre

Physicians and Surgeons, l'Association des Medicins de Langue Francaise du Canada and the Canadian Nurses Association) which has established minimum standards for hospital accreditation.[1] This Council has not only been a powerful factor in raising quality, but also has advocated, on paper at least, that basic patient rights in hospital be assured.[2] The preamble of the Hospital Accreditation Manual (1972) contains three pages describing patient rights and subsequent professional obligations to protect these rights, stating that the Council commends observance of these rights in practise as a "basic philosophy of all those involved in hospital services."[3]

Consumer Interest

In concluding this discussion on consumer rights, it would be a serious oversight to neglect mention of various voluntary associations which have been active in promoting consumer rights in health care. Activities of the Consumer Association of Canada have already been mentioned in this regard.

The Saskatchewan Association on Human Rights has devoted attention to health care rights in the publication of a position paper on Health Care Rights, and a supplement to this position paper entitled

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[1]Canadian Council on Hospital Accreditation, Guide to Hospital Accreditation, 1977, p. v.

[2]Ibid., pp. xxv-xxvii.

[3]Ibid., preamble, pp. xxv-xxviii. Note that this very excellent preamble, on patient rights, was not repeated in the 1977 Manual.

Needless Surgery. These briefs were presented to the Government of Saskatchewan in December 1975 following two years of urging the Government to conduct an inquiry into hospital care and practises. The position paper contains recommendations for a patient's Bill of Rights,[1] a Health Professional's Bill of Rights,[2] corporate accountability and accessibility, and many other recommendations.

In addition to the above associations, patient associations have emerged as patient advocate organizations. In Quebec in 1975, patients formed a union to defend the rights of Quebec's 25,000 elderly, handicapped and chronically ill, aiming to help patients recover their dignity and maintain their autonomy.[3] A Patients' Rights Association was formed in Ontario, also in 1975, because of difficulties members of the public encountered in dealing with various health professionals in Ontario. The Association handles complaints or advises people where to direct their complaints; and promotes among the general public awareness of health rights and responsibilities.[4]

Consumers have also been joined by a few doctors and other health professionals willing to speak out against the establishment and in favor of patient rights. The author of Saskatchewan's Health Care Rights

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[1]Health Care Rights, by John J. Marian, Chairman (Saskatchewan Human Rights Association, 1975): 32-33.

[2]Ibid., pp. 40-41.

[3]"Quebec Patients Form Union," Dimensions in Health Service 52 (April 1975): 27.

[4]AIMS, Ontario's Patients' Rights Association, p. 3 Constitution and By-Laws.

position paper is one of these, as is a Toronto doctor who, along with a group of thirty professionals and laymen, publishes The Critical List, sold on newsstands. The Critical List provides a forum for doctors and others to express anti-establishment views in a constructively critical manner.[1]

Conclusion

Rights to health care and rights in health care are the foci of consumer rights concerns in health care. Recognizing the many possibilities for violation of patient/consumer rights, the American Hospital Association in 1972 issued a Statement on a Patient's Bill of Rights which was accorded much attention. In 1974, the Consumers' Association of Canada issued a Charter on Consumer Rights in Health Care which includes four main points: the right to be informed, the right to be respected, the right to participate, and the right to equal access to care. Exercise of these rights returns some degree of control to the consumer, as well as some responsibility.

Health professionals have a role to play in returning some control and responsibility back to the consumer of care. Particular attention will be directed in the remaining chapters toward the nursing profession and its role in consumer rights. Before proceeding with a discussion of nursing and consumer rights, however, a very brief digression will be taken to examine one very significant activity in consumer rights, the patient representative.

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[1]"The Critical Viewpoint," (editorial) The Critical List 1 (March 1976): 3-4.

CHAPTER 6

THE PATIENT REPRESENTATIVE

> In a sense, speaking ideally, every hospital employee assumes at one time or another some of an ombudsman's duties, but specific job assignments are demanding and the need for the special person to take on the time-consuming responsibility for this specialized, yet varied work has become apparent, most particularly in the large hospital in an urban setting.[1]

The past decade has seen the growth of a new type of health care worker known variously as the patient representative, the patient advocate, or the patient ombudsman. To date, this worker has largely confined his duties to representing patients within the hospital setting.

In that the patient representative constitutes a very tangible and significant activity of consumer rights in health care, a brief discussion of the emergence and present function of this new worker would seem imperative. Central, and largely unanswered, questions in this discussion are some of the following: Is this new worker necessary? Does the existence and growth of the patient representative constitute an acknowledged failure of professionals and health organizations to be responsive to patient rights? Where does this new worker fit in relation to other health care workers? Should this new worker be a health care professional or an outsider?

The emergence and spread of the patient representative idea seems to have been contingent upon two separate but related factors. On

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[1]G.A. Guzwell, "The Hospital Ombudsman," Hospital Administration in Canada 16 (August 1974): 15.

the one hand, there has been a growing concern as hospitals developed in the post-war period, for public relations programs.[1] On the other hand, the creation of ombudsmen offices in various parts of the world including North America, particularly in the fifties and sixties, would seem to have been an indirect influence.

While this author would have to admit that the former influence, rather than the latter, has been by far the more significant factor, the emergence, growth, problems, and prospects of the patient representative role and function bears striking similarity to that of the ombudsman. Therefore brief attention will first be directed to the ombudsman phenomena.

Ombudsmen: Rise, Role, Requirements

Derivation of the term ombudsman is Swedish and may be "translated loosely as citizen's defender, grievance man, or public watch-dog."[2] While the Swedish Parliament created the office of the ombudsman as early as 1809,[3] followed by creation of a similar office in Finland in 1919,[4] it was not until Denmark appointed its first

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[1]See for example, Donald P. Fish, "Public and Patient Relations," Canadian Hospital 40 (November 1963): 51-53, 76. "A Hospital Public Relations Officer," (editorial) New England Journal of Medicine 248 (May 7, 1953): 832-833.

[2]Donald C. Rowat, The Ombudsman Plan: Essays on the Worldwide Spread of an Idea (Toronto: McClelland and Stewart, 1973): preface, p. vii.

[3]Alfred Bexelius, "The Origin, Nature and Functions of the Civil and Military Ombudsmen in Sweden," in Annals of the American Academy of Political and Social Science, Vol. 377, The Ombudsman or Citizens' Defencer: A Modern Institutions (May 1968): 11.

[4]Walter Gellhorn, Ombudsmen and Others (Cambridge: Harvard University Press, 1966): 50.

ombudsman in the mid-fifties that the idea spread.[1]

Sawer cites several reasons for the growth and spread of the ombudsman idea, but basically relates these reasons to the question of "who governs the government?"[2] Since World War I, there has been a growing concern in democratic countries that the democratic process and the law, between them, are inadequate to deal with the grievances of citizens against government.[3] Rowat states that whereas in the past, courts were seen as the bulwark of human rights, they have lost their flexibility and no longer are seen as an effective instrument to remedy the wrongs of administrative action.[4]

Societal change, as described in chapter 2, has not only increased the size and numbers of bureaucracies, but, as Sawer notes, the growing welfare state has multiplied the opportunities for individual grievance.[5] Possibilities exist for consumer rights to be "accidentally crushed" by the government's administrative machinery.[6] Rowat quotes Dicey in suggesting the root of the problem: "Wherever there is discretion, there is room for arbitrariness."[7] A former

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[1]Hing Yong Cheng, "The Emergence and Spread of the Ombudsman Institution," in Annals of the American Academy of Political and Social Science, Vol. 377, The Ombudsman or Citizens' Defender: A Modern Institution (May 1968): 21.

[2]Geoffrey Sawer, Ombudsmen (New York: Cambridge University Press, 1964), p. 1.

[3]Ibid., p. 1.

[4]Rowat, p. 47.

[5]Sawer, p. 1.

[6]Rowat, p. 46.

[7]Ibid., p. 46.

Alberta ombudsman supports Dicey's statement when he states:

> . . . some people believe discrimination, and injustice the citizen suffers at the hands of the government stems from rogues and sadists. On the contrary, such indignities usually flow from people who are uninformed of the true facts; who are careless; who are stupid or lazy or puffed up with office.[1]

The ombudsman's function, then, is to defend the citizen/the consumer against governmental mistreatment whatever its cause. In order to carry out this task, certain characteristics of the position are essential. The ombudsman must be an impartial authority, entirely independent of administration; the ombudsman acts on behalf of parliament although he is also protecting the interests of the individual complainant; the ombudsman conducts investigations openly; and both the method of submitting complaints and the investigation of complaints are informal mechanisms.[2]

Independence of the ombudsman office is central to effective functioning. Lacking this independence from administration's control, the ombudsman can be severely hampered in his investigations.[3] The original ombudsman offices were clearly responsible to parliament only.[4]

Another important characteristic of the office seems to rest

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[1]Report of the Ombudsman, (George B. McClellan), Province of Alberta, 7th Annual Report (November 1, 1972 - October 31, 1973), p. 14.

[2]Rowat, p. 49.

[3]In some cases the Ombudsman has had to establish his independence. See for example Alex B. Weir, "The Legislative Ombudsman," Alberta Law Review 14:2 (1976): 259.

[4]Bexelius, p. 12.

with the personality of the ombudsman.[1] Friedmann describes the personality as of overwhelming importance.[2] Others have suggested that a mix of tact, kindness, aggression, and persistence are essential.

> A good ombudsman will reduce the complacency, verging towards arrogance, which is the characteristic vice of bureaucracies, and he will also remove many chips on shoulders which citizens tend to display in their dealings with government.[3]

Ombudsmen - Reception, Variations, Restrictions, Contributions

We might predict that the introduction of the ombudsman office would not be greeted enthusiastically by all concerned parties. In most cases, civil service groups and government departments were in opposition to the idea.[4] But advantages have accrued to governmental employees. In many cases the ombudsman's investigation has served to exonerate the government department or the civil servant from wrong-doing.[5] More often, an ombudsman may detect incorrect procedures, or shortcomings in legislation, and begin corrective measures,[6] which assist the civil servant in his work.

As the ombudsman institution has spread to governments of other countries, provinces, or cities, the role and function has been modified

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[1]Sawer, p. 47; Rowat, p. 24.

[2]Karl Anton Friedmann, "The Alberta Ombudsman," University of Toronto Law Journal 20 (1970): 52.

[3]Sawer, p. 49.

[4]Bexelius, p. 11; Gellhorn, p. 7, 91.

[5]Rowat, p. 10, 27.

[6]Bexelius, p. 17.

to suit various political and social conditions. Particularly in developing countries, the ombudsman is not likely to be endowed with the power and independence necessary for the position, and thus his ability to function will be restricted.[1] In addition, different countries have tended to develop different main areas of grievance which affect the style and organization of the office.[2] Some ombudsmen are severely restricted in their jurisdiction over courts, administrative tribunals, or local governments.[3] Some have widespread powers to receive complaints, conduct investigations at all levels of government, and initiate investigations on the basis of their concerns. Other ombudsman offices appear to be similar to public relations offices only.[4]

Ombudsmen may also be restricted in their function if either the ombudsman lacks sufficient support staff so that complaints and concerns might be investigated fully and quickly, or if citizens are not well-informed of the existence and purpose of the ombudsman.[5] Friedmann, citing results of a survey regarding citizen knowledge about the Alberta ombudsman, concluded that those who most needed the ombudsman were likely to know the least about him and, therefore, the least likely to use the opportunity for seeking re-dress available in the ombudsman.[6]

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[1]Rowat, p. 137

[2]Sawer, p. 46.

[3]Gellhorn, pp. 11-12; Weir, pp. 257, 261. Weir discusses three provincial ombudsmen's jurisdictions challenged, viz. the RCMP in Saskatchewan, a District Advisory Planning Commission in Manitoba, and a Mental Board of Review in New Brunswick.

[4]Weir, p. 257.

[5]Friedmann, p. 50.

[6]Ibid., p. 55.

There are now eight provincial legislative ombudsmen in Canada,[1] and the ombudsman idea has been adopted worldwide.[2] What are the contributions of the ombudsman? Do we need such an office?

Many authorities of the ombudsman plan are quick to point out that the ombudsman institution is in no way "an all-inclusive cure-all for society's ills."[3] The basic mechanism of judicial control, internal control, and administrative appellate systems cannot be substituted by the ombudsman.[4] However, many times these ordinary remedies are inadequate and there is a need for an independent organ for the complaint, in order to assure good government.[5] Bexelius, Swedish ombudsman, sees an expression of genuine democracy when a society will establish a special institution charged with ensuring that other agencies serving the society respect the rights of citizens.[6] Rowat sees the need for an ombudsman for Canada for two reasons. Under Canada's parliamentary system, which involves executive dominance over legislation, and because of a tradition of secrecy, there is no easy way for cases of maladministration to come to light.[7] He further accuses Canada of being complacent over the protection of citizen rights,

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[1] Report of the Ombudsman, Province of Alberta, 9th Annual Report (November 1, 1974 - October 31, 1975), p. 4.

[2] Rowat, pp. 117-144

[3] Weir, p. 257; see also Bexelius, p. 18.

[4] Gellhorn, p. 255.

[5] Bexelius, p. 18.

[6] Ibid., p. 19.

[7] Rowat, pp. 86-89.

> . . . perhaps engendered by the strength of the inherited British tradition that the citizen is fully protected by the 'rule of the law.' We do not realize that, due to the modern growth of administrative powers, the meaning of this tradition has lost much of its context. . . .[1]

Apart from the obvious benefits of an appeal channel and a facilitator of corrective measures for poor legislation or procedure, Sawer suggests that the total impact of the ombudsman's activities on the public administration is greater than the cumulative importance of the cases with which the ombudsman deals.[2] Mere existence of the ombudsman office acts to sharpen the attention of authorities to power abuses.[3] The educational force of the ombudsman's work is seen as a highly significant contribution to the protection of citizens' rights.[4]

Patient Representatives: Rise, Role, Requirements

Because the literature regarding patient representatives is as yet spotty, to a considerable extent this discussion of the patient representative relies upon the personal experience of the writer's attendance of a workshop and annual meeting of the Society of Patient Representatives.[5] The Society of Patient Representatives is a relatively new society of health workers occasioned by the rise of the health care worker generally known as the patient representative.

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[1]Ibid., p. 96.

[2]Sawer, p. 49.

[3]Bexelius, p. 16.

[4]Gellhorn, p. 35.

[5]The 5th Annual Meeting of the Society of Patient Representatives of the American Hospital Association, Hyannis, Cape Cod, Massachusetts, October 5-8, 1976.

Some reasons for the emergence of this new worker have been alluded to early in this chapter. Increasing bureaucratization of hospitals and other health care agencies, increasing division of labor among health care providers, as well as a change in values coupled with other major societal changes, have created a situation in which patients/consumers seem to require an ombudsman or patient's defender. The variety of health care organization changes discussed in chapter 3 have created situations in hospitals and other health care agencies where consumer rights can be "accidentally crushed." As in the case of the legislative ombudsman, failure to honor consumer rights may also occur because staff are uninformed, careless, lazy, or inflated by their office.

The function of the patient representative, then, is to defend the patient against mistreatment (either from acts of omission or commission) by health care providers whatever the cause. The representative also serves as a specific channel through which patients can seek solutions to problems, concerns, or unmet needs in the health care system.

Services to the patient include seeking out those individuals who have problems; talking to patients to identify the source of difficulty; determining appropriate action to provide suitable care; negotiating institutional red tape on behalf of the patient; providing information about the organization and its services; making referrals to other departments; and providing a very essential follow-up to determine that satisfactory service has been rendered.[1]

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[1]Information compiled from American Hospital Association printouts on The Patient Representative. (See Appendix C)

For the institution the patient representative provides a centralized, consistent patient grievance mechanism; a central source of information and referrals; a monitor for patient experience and perceptions; a monitor for problem areas regarding department or staff which may need review; and a research and documentation center for obstacles requiring change.[1]

Essential requirements of the role are the same as those of the government's ombudsman. The patient representative must be allowed independence in order to be effective. Ideally a patient representative should report to top administration, or conceivably the hospital board. While the representative acts on behalf of the hospital, he is there to represent the interests of the patient and must be free to do so.

Requirements of personality are no less imperative for this role than for the role of the legislative ombudsman. Given the complexities of hospital structure and staff relationships, a patient representative must be skilled in dealing with all types of staff as well as all types of patients. "Effective functioning in this position requires much tact and skill"[2] in dealing with others.

Patient Representatives - Reception, Variations, Organization

As in the case of legislative ombudsmen, it would seem that hospital staff have often been initially suspicious of the patient representative

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[1]Ibid.

[2]"Hospital Social Workers and Patient Representatives," Hospitals, J.A.H.A. (May 1, 1974): 14.

who they may see as someone monitoring their performance or interfering with patient care. However, as benefits to staff have accrued by contact with this independent facilitator, acceptance has generally been favorable.

The thrust in the emergence of the patient representative occurred in the context of hospital concerns for public relations. In the fifties, many United States hospitals moved to hiring a full-time public relations "girl", or sometimes a hostess, in order to make patients' hospital stays more pleasant, and to relieve some of the pressure on the professional staff.[1] In some of these positions, the employee in fact acted on behalf of the patient (as a patient representative), but in the majority of cases the job functions consisted of personal services such as writing letters for the patient, arranging accommodation for relatives, serving coffee or tea, shopping for the patient, and general hostess-type functions.

As the patient representative idea has become adopted in various parts of North America, hospitals have specified various key functions to be performed by this worker dependent upon the socio-political environment of the institution and specific needs. Many U.S. hospitals have used patient representatives in connection with their finance department.[2]

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[1]Donald W. Cordes and Susan B. Enyart, "Why We Hired a Full-Time Patient-Relations Girl," Hospitals, J.A.H.A. 32 (September 1, 1958): 19-22. Edith S. Oshin, "She Runs Interference for Nurses," RN 26 (April 1963): 78-85.

[2]"Representative Gives Patients Personal Service," Hospitals, J.A.H.A. 42 (June 16, 1968): 41; Margaret Emrich, "Patient Relations Representative: More Than Hospital Hostess," Hospital Topics 49 (September 1971): 43-46. Betsy M. Clapp, et al. "Seven Steps to Setting-up a Patient Representative System that Works," Hospital Financial Management 5 (October 1975): 42-47.

In such cases the patient representative is generally responsible for greeting the patient on admission, following him through to discharge and assisting with all problems related to health insurance or additional finances needed. A given hospital may employ 15-20 such workers entitled patient representatives for this type of function.

Some hospitals have continued to employ persons performing the hostess function, but under the job title of patient representative. Yet other hospitals have emphasized the ministry to the patients' psychological and spiritual needs in their patient representative program.[1]

In some situations, certain areas of the hospital become targets for attention by the hospital in the patient representative program, such as emergency rooms or clinic settings.[2] Mental institutions have utilized patient representatives to inform patients of their rights and responsibilities, and to help them advocate for themselves.[3] Other mental hospitals have used a patient advocate or representative to investigate all patient complaints including those related to the

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[1]Sr. Mary Modesta, "Patient Relations Representatives Bridge Communication Gap," Hospital Progress 51:10 (September 1970): 30-32; "Another Kind of Ombudsman," Modern Hospital 114:1 (January 1970): 94-95.

[2]Dorothy M. Morgan, "At Montreal General: The Patient Advocate - A New Aid for Emergency," Canadian Hospital 50:8 (August 1973): 24-25, 53; Richard Cavalier, "Ombudsman is Middle Man Between Patients and Hospital," Modern Hospital 114:1 (January 1970): 92-94, 96.

[3]Roy A. Ettlinger, "Advocate Informs Patients of Rights and Responsibilities," Hospital and Community Psychiatry 24:7 (July 1973): 465.

commitment law and patient treatment.[1] In Alberta, the legislative ombudsman's services have been (and continue to be) enlisted to a considerable extent by patients in provincial mental hospitals, as is evident from the ombudsman's annual reports.

In many cases the patient representative has been hired by a hospital in an attempt to contain the threat of hospital malpractise liability. In some states, hospitals are able to secure a two percent reduction in hospital insurance premiums if the hospital employs a patient representative.[2]

Generally, the emerging patient representative of the seventies, in whatever area or type of hospital he or she may serve, is patterned after the legislative ombudsman, as a protector of the patient, a defender of rights, a referee for fair play, arbitrator, and impartial judge.[3]

By 1971, when a group of ninety three representatives met to establish a Society of Patient Representatives in affiliation with the

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[1]Bill Johnson and David Aanes, "Patients' Use of a Full-Time Advocate in a State Hospital," Hospital and Community Psychiatry 25 (July 1974): 445-446. See also, Grant Dobson and R.C. Hansen, "The Ombudsman in Mental Health: Lakeshore's Experience," Canada's Mental Health 24 (September 1976): 11-13.

[2]This information was obtained by discussion with participants at the Meeting of the Society of Patient Representatives.

[3]Guzwell, p. 15. See also Sr. Louise Marie, "The Hospital Ombudsman," Hospital Forum 15 (May 1972): 6-8; "Ombudsman Gives Hospital Patients Voice," Canadian Hospital 50 (September 1973): 13; Wanda C. Nations, "Nurse-Lawyer is Patient Advocate," American Journal of Nursing 73 (June 1973): 1039-1041.

American Hospital Association,[1] membership was open to all hospital employees whose job included: 1) patient representation as constituting their primary assignment; 2) patient advocacy to hospital administration; 3) direct representation of management to the patient; and 4) a specific channel function through which patients can seek solutions to problems.[2] Generally, the Society tried to exclude finance-orientated patient representatives.

One of the Society's aims was to help other hospitals set up plans for patient representative programs.[3] Within the Society membership are three Canadian patient representatives, of approximately a dozen of such positions in Canada.

Presently the Society consists of patient representatives from a wide variety of backgrounds, but basically performing the patient representative function outlined by the Society. Among the membership are former volunteer workers, admitting clerks, personnel officers, airline hostesses, administrative assistants, social workers, clergy and nurses.[4] Within the membership at the present time there are those

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[1]"Patient Ombudsman Urged to Restore Human Element," Hospitals, J.A.H.A. 46 (November 16, 1972): 109.

[2]"Her Assignment is to Humanize the Hospital," Hospital Practise 9 (February 1974): 49-56.

[3]"Hospital Ombudsmen form National Organization," RN 34 (December 1971): 67-70.

[4]Patient representatives who are graduate nurses constitute approximately one-third of the Society's present membership of close to 500. When the Society was established, half of the patient representatives were nurses.

anxious to become "professionals"[1] and, according to several participants in the Annual Meeting, those equally anxious not to become professionals lest they lose touch with the patient they are employed to serve.

Restrictions of the Patient Representative Role

Several restrictions related to the functioning of the patient representative are apparent. The need for adequate representation of a large number of patients twenty-four hours a day is causing some hospitals to increase their number of patient representatives while others work out varying strategies to attempt to serve the patients. Ensuring patient awareness of the services of the patient representative is another concern. Much attention appears to have been given to the production of cards or folders destined for the patient's bedside table in order to inform him about the patient representative program.

Few representatives appear to be empowered to deal with complaints relating to physician care. Where these complaints are also being investigated by the patient representative, the license to do so usually has occurred because the patient representative has managed to establish utility and credibility in the physician's eyes rather than by any structural support in the hospital system.

An additional concern has been the potential conflict of interest for the patient representative. Though the need for independence of function is generally acknowledged by the representative, the majority

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[1]Ruth Ravich, "Patient Relations," Hospitals, J.A.H.A. 49 (April 1, 1975): 107.

are tied into positions where they are accountable to another department in the hospital. However, even when the representative is accountable to top administration only, conflicts can develop where the patient representative is not able to represent both the best interests of the patient and the hospital.

Contributions of the Patient Representative

Many questions have been raised regarding the need for patient representatives in the health care industry. Some have expressed the opinion that patient representatives would not be necessary if the existing health care providers did their jobs properly. This view would encourage that attention be directed toward re-educating present workers to function more effectively. In addition, some nurses identify consumer advocacy as part of nursing's present role and function.[1] However, in spite of the fact that isolated nursing leaders have urged nurses to practise an advocacy function, there is little evidence of either an understanding of or a commitment to such a function among nurses generally.

The realities of the situation do not seem to vary substantially from the factors necessitating the office of the parliamentary ombudsman. Size and complexity of hospitals and other health care agencies, and the multiplicity of workers involved in health care provision, foster some inevitable gaps in patient care. Health care providers would be deceiving themselves if they failed to acknowledge that such gaps in

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[1]"Nursing '73: Time for New Leadership," Nursing Outlook 21 (April 1973): 227.

patient care exist.

While creation of the office of a patient representative can be no substitute for genuine care and concern for patients and patients' rights by all staff, it can logically be argued that the patient representative can act as a supplement to the caring which already exists. Some feel that a patient advocate is required to ensure that the Patient's Bill of Rights is actively practised.[1] Presence of a patient representative may serve to sharpen health providers' awareness of patient "abuse," and also may serve as a powerful educational tool. Several writers urge that the patient representative be welcomed as a new member of the health care team who can assist staff in ensuring that consumer rights are in practice.[2]

Conclusion

A parallel has been drawn between the office of the hospital ombudsman and the hospital patient representative. Striking similarities relating to role, restrictions, and requirements of the position are apparent. Furthermore, if the patient representative idea spreads, it would seem important that greater attention be given to the well-established ombudsman offices as role models.

Admittedly, the role of the patient representative differs from the ombudsman role because of the intra-institutional rather than the

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[1]George J. Annas and Joseph Healey, "The Patient Rights Advocate," Journal of Nursing Administration 4 (May-June 1974): 25-31.

[2]Oshin, p. 85; Guzwell, p. 16.

extra-institutional setting; and the patient representative is not likely to achieve the degree of independence of a legislative ombudsman. In spite of this limitation, it would seem that patient representatives have to a considerable extent been successful in meeting many unmet patient needs. Whether a patient representative is necessary to assure the implementation of patient/consumer rights, or whether the unmet needs could be fulfilled by existing health care providers will be discussed further in the remaining chapters.

PART IV

NURSING AND CONSUMER RIGHTS

CHAPTER 7

NURSING: PAST AND PRESENT

Nursing has great potential to affect consumer rights in health care. Not only has nursing the asset of great numbers, in being the most common professional variable in the health care system, but nurses are also distributed throughout the health care system. Furthermore, the nurse, generally more than other health professionals, has sustained contact with the patient.

In view of this tremendous potential, what are the central issues in nursing which may help or hinder the ability of nurses to be responsive to consumer rights? To identify and examine some of the issues, Warren's seven aspects of community change will again be employed to focus on nursing in the past and in the present.[1]

Division of Labor

Before the era of the modern hospital, patient care took place primarily in the home. While the majority of patient care involved neither doctor nor nurse, when outside help was sought from a professional, the working relationship between doctor and nurse was generally warm and friendly.

> Under such circumstances, it was easy for the nurse to report the patient's condition and attitudes in detail to

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[1]Roland Warren, The Community in America, 2nd edition (Chicago: Rand McNally and Company, 1972): chapter 3.

> the doctor when he made his frequent housecalls. It was equally easy for him to discuss his recommendations in an informal way. The strong team relationship that frequently existed must have helped greatly to maximize the quality of patient care.[1]

The patient, too, felt a participatory role in the care process. The doctor advised the need of a nurse, "his nurse" whom he would send, and the patient or his family made the decision to hire "his nurse." Both doctor and nurse supported an image of confidence in the other, giving the patient incentive to cooperate in recovery or to face death supported by a two-member team.[2]

As the modern hospital developed, much of patient care shifted from the home to the hospital. With that shift in locale, and as a result of the underlying reasons for the shift, "nursing" functions became increasingly divided among various workers and the two-member team for patient care expanded. While the nurse continued to be generally regarded as in charge of the "whole" patient, various segments of patient care (formerly all in the realm of "nursing" care) have become the work of other specialists, such as physiotherapists, respiratory technicians, dietitians, housekeepers, and many others.[3] Mauksch describes this division of function as analagous to cookie dough from which numerous

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[1]Esther Lucile Brown, "Nursing and Patient Care," in The Nursing Profession, ed. Fred Davis (New York: John Wiley and Sons, Inc., 1966), pp. 178-179.

[2]Ibid., p. 179.

[3]Hans O. Mauksch, "The Organizational Context of Nursing Practice," in The Nursing Profession, ed. Fred Davis (New York: John Wiley and Sons, Inc., 1966), p. 124.

cookies have been pressed. The remaining dough represents the unity and scope of nursing care, while the cookies represent the functions removed from nursing which have developed into independent specialties. During evening and night hours and weekends nursing is again expected to take responsibility for many of those areas which have become independent "cookies."[1]

In addition to the growth of specialists providing segments of what used to be total "nursing" care, further division of labor has occurred within nursing itself. While "practical" nurses, as opposed to "professional" nurses, were in existence at the turn of the century,[2] impetus was given to the growth of auxiliary workers in nursing care as a result of the shortage of nurses experienced during World War II. These workers, recruited to augment nursing staff, became known as nursing aides and nursing technicians.

Though the nursing profession had initially not supported the idea of this new worker in the hospital, the possible utility of such an intermediate worker was eventually accepted and the expansion of the group of nursing aides was encouraged.[3]

> Nurses are delegating much of their former work to practical nurses, aides, and maids, while continually taking on new

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[1]Ibid.

[2]Anna Louisa Davis, "The Value of the Practical Nurse," Canadian Nurse 10 (October 1914): 621, 624; "The Supply of Practical Nurses," Canadian Nurse 15 (February 1919): 1577-1588.

[3]Brown, p. 187.

> duties assigned to them by physicians and administrators of hospitals.[1]

Generally, the tasks delegated by nurses were those which they downgraded, such as bed-making and housekeeping duties.[2] Wilensky describes this delegation process as consistent with other professional groups in short supply who re-define their functions upward and "slough off their dirty work, that is, their less technical or less-rewarding tasks."[3]

But while many professional groups have been considerably successful in discarding selected functions, this process of delegation of function to auxiliary workers has created substantial on-going problems for the nursing profession. Merton, a prominent sociologist, suggests that problems arise because the difference between the nurse and the auxiliary worker is a difference in degree of responsibility for the function, not in the type of function. Furthermore, both auxiliary worker and registered nurse comprise parts of one another's work environment, which factor is likely to accentuate concerns of comparative status.[4] Many registered nurses would argue that there is a difference in type of function, and in many cases a separation of work environments, as for example in intensive care units, hemodialysis units, or nursing

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[1]Everett C. Hughes, Men and Their Work (Glencoe, Illinois: The Free Press, 1958), p. 135.

[2]Ibid.

[3]Harold L. Wilensky, "The Professionalization of Everyone?" American Journal of Sociology 70 (September 1964): 144.

[4]Robert K. Merton, "Status-Orientations in Nursing," in Social Interaction and Patient Care, ed. James K. Skipper and Robert C. Leonard (Toronto: J.B. Lippincott, 1965), p. 381.

homes, where either registered nurses or nursing aides predominate.

Nevertheless, the existence of some confusion of roles in nursing is a problem for both nurses and the general public. As well as the registered nurse-nursing aide divisions, there are status divisions between registered nurses and baccalaureate degree nurses, where appropriate division of labor based on type of expertise is not always clear or acceptable to all staff.

With the increase in categories of nursing staff there was a trend away from individualized nursing care (as modeled after private duty nursing) to functional nursing care, in order to provide care to the large numbers of patients. In functional nursing, one nurse made all the beds, one handled all the medications, another did all the treatments, etc. This type of organization of nursing care eventually gave way to team nursing, an arrangement which gave staff the "psychological support" of working in a small group.[1] The search for a satisfactory organization of nursing care has continued[2] and appears to be contingent upon the trends of the particular time-period, the needs and capabilities of the organization, the needs of the nurses, and (one would hope) the needs of the patients. "Primary nursing" is gradually becoming the vogue today, i.e., a nurse being accountable for one or two patients for the entire length of their stay. "Primary nursing" appears to represent an attempt to return to individualized

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[1]Brown, p. 190.

[2]Pre-requisite for Nurse-Physician Collaboration: Nursing Autonomy," Nursing Administration Quarterly 1 (February 1976): 49.

nursing care.

Added to the problems and prospects of division of labor in nursing care and the division of labor in para-medical patient care, is the division of labor within the nurse-doctor team. Doctor dominance on this team has been described as problematic. While this pattern is not entirely new to nursing,[1] the hospital setting has accentuated the awareness and concern of nurses and others to the problem. Increasing size and complexity of the hospital has resulted in decreased personal acquaintance between nurse and doctor, with a subsequent loss of confidence and trust.

Many reasons for doctor dominance in the doctor-nurse relationship have been suggested, including some of the following: that most nurses are female and most physicians are male; that schools of nursing, formerly based on an apprenticeship system, have not developed independent thinkers; that nurses do not have the same level of education as the physician; and that nurses generally come from a lower socio-economic class than physicians.[2] While each of these factors may have some impact on the doctor-nurse relationship, there may be a tendency to use the reasons as excuses for a poor relationship, or to over-emphasize any one reason and thereby diffuse attention from establishing a better relationship.

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[1]E.g., see Florence Nightingale, Notes on Nursing (London: Bookseller to the Queen, 1859), p. 74.

[2]Beatrice J. Kalisch and Philip A. Kalisch, "An Analysis of the Sources of Physician-Nurse Conflict," Journal of Nursing Administration 7 (January 1977): 52-53. See also, Fred E. Katz, "Nurses," in Semi-Professions and Their Organizations, ed. Amitai Etzioni (New York: The Free Press, 1969): 59; Nightingale, p. 74.

Interactional patterns of physician-nurse relationship have been described by Stein in a classic article in which he calls the behaviour patterns a "game". The central characteristic of the "game" is that the nurse takes much initiative and responsibility while appearing to remain passive, allowing the physician to make all the recommendations.[1] While the "game" arises out of perceived physician dominance and omnipotence, Stein suggests that it is perpetuated by all those factors that cause nurses to defer to physicians, particularly the sexual role stereotype.[2] Stein's description appears to have been considerably accurate at the time of writing (1968) and continues to be valid today.

That the game pattern of relationship is not in the best interests of the patient/consumer is clear. More than a century ago, Nightingale was bold enough to suggest that the nurse has a much better base from which to advise the doctor since the doctor rarely sees the patient more than once per day.[3] A prominent Canadian nurse refers to a "reverse-Cinderella syndrome" occurring on hospital wards. In the daytime, responsibilities of the doctor and nurse are fairly clear, and limited for the latter. At night, particularly in understaffed or rural hospitals, the same nurse is "capable" of suturing, delivering babies, and instituting various forms of therapy.[4]

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[1]Leonard Stein, "The Doctor-Nurse Game," American Journal of Nursing 68 (January 1968): 101-105.

[2]Ibid. [3]Nightingale, p. 42.

[4]Helen Mussallem, "Physician's Associate Also Means Patients' Friend," The Medical Post (March 23, 1971): 30.

The doctor-nurse interaction pattern described above requires change. While some purport that it is possible to achieve change through individual attitudinal change among both nurses and doctors, it may be necessary to change the organizational structure of health care to effect broader attitudinal and behaviour change.[1] The issue is not who shall dominate, but rather a re-establishment of a mutual respect and confidence in each other's person and profession so that "games" are not required.

Problems of professional status within the division of labor plague nurses; and the place of nursing among the professions has been a controversial issue.[2] In the conclusion of the report of the National Commission for the Study of Nursing and Nursing Education, the following statement was made:

> Yet nursing has been and is a troubled occupation. It is an occupation that fails in every characteristic to achieve the status of a full profession, despite the fact that its best practitioners are professional in every sense of the word.[3]

After examining and comparing nursing of the 1920's and nursing of the 1960's, Stinson concluded that while nursing was undergoing a

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[1]"Pre-requisite for Nurse-Physician Collaboration: Nursing Autonomy," Nursing Administration Quarterly 1 (February 1976): 60-61. See also F. Jo Logan, "The Handmaiden is Not Dead," Canadian Nurse 72 (May 1976): 25.

[2]See for example, William J. Goode, "The Theoretical Limits of Professionalization," in The Semi-Professions and Their Organizations, ed. Amitai Etzioni, p. 267; Katz, p. 71.

[3]An Abstract for Action. National Commission for the Study of Nursing and Nursing Education. Jerome P. Lysaught, Director (Toronto: McGraw Hill Book Co., 1970): 163.

process of professionalization in the twenties, nursing in the sixties appeared to be undergoing a process of "deprofessionalization" or "occupational disintegration."[1] This conclusion was based upon the following characteristics of nursing.

> Firstly there has been a deterioration of the substantive knowledge-skill component, a decline in the aura of mystery, lack of theoretical development and inadequate development of methodology suitable to research in nursing, and adaptations to technological innovations have, by and large, taken the nurse away from the patient, her chief locus of nursing knowledge. . . . Secondly, increased responsibility has not been accompanied by a concomitant increase in authority. . . . Thirdly, the socialization of recruits would seem to be inadequately articulated with the realities of what are highly bureaucratized work-settings.[2]

While greater attention has been directed to the area of theory development since the late sixties, the above bases for deprofessionalization would still seem to be extant today.

As nursing seeks to enhance its professional status, the crucial questions to be answered are:

> Professionalization for what purpose? For the good of the profession? For the good of the public which it professes to serve? Or, for both?[3]

Differentiation of Interests and Associations

A move to establish associations for nurses was begun before the

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[1]Shirley M. Stinson, "Deprofessionalization in Nursing?" (Ed.D. dissertation, Teachers' College, Columbia University, New York, 1969): 377-378.

[2]Ibid., pp. 378-379.

[3]Juanita F. Murphy, Theoretical Issues in Professional Nursing (New York: Appleton Century Crofts, 1971): 4.

turn of the century.[1] Initial concerns related to licensing, accreditation of schools, and improvement of recruitment, selection and education. In order for Canadian nurses to be represented in the International Council of Nurses (I.C.N.), the Canadian Association of Trained Nurses was formed in 1908, a precursor body to the present Canadian Nurses' Association (C.N.A.).

In the years during and following World War II, a unified voice of nurses, represented in the Canadian Nurses' Association, was called upon to participate in decision-making related to health care problems on a national scale. The severe shortage of nurses during the war prompted the CNA to search for new sources of nursing personnel and, as a consequence, to develop a curriculum guide for training nursing assistants.[2] At the same time, concern for recruitment to nursing caused the CNA to establish a committee on labor relations (1943) in order that nursing might plan to be competitive in its appeal to recruits This action "ultimately led to the CNA's endorsement of collective bargaining."[3]

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[1]In 1893, at the World's Fair in Chicago, Nursing leaders gathered to discuss standards of nursing and administrative practices of schools of nursing. In 1896, the Nurses' Association Alumnae of the United States and Canada was formed; and in 1899, the International Council of Nurses came into being as a federation of lay nurses with professional aspirations. See Rosamund C. Gabrielson, "Two Centuries of Advancement: From Untrained Servant to Skilled Practitioner," Journal of Advanced Nursing 1 (July 1976): 269; The Leaf and the Lamp (Ottawa: Canadian Nurses' Association, 1968): 34-35; William A. Glaser, "Nursing Leadership and Policy: Some Cross-National Comparisons," in The Nursing Profession, ed. Fred Davis (New York: John Wiley and Sons, Inc., 1966): 17.

[2]The Leaf and the Lamp, p. 88. [3]Ibid., p. 8.

In 1947, the CNA was incorporated under the Statutes of Canada as a federation of provincial associations. In 1966, the CNA's objectives were revised to state that the CNA existed:

1. to promote high standards of nursing practice in order to provide quality nursing care for the people of Canada;
2. to promote educational programs required to achieve high standards of practice;
3. to encourage an attitude of mutual understanding and to promote unity among nurses;
4. to speak for Canadian nursing and to represent Canadian nursing to other organizations on national and international levels;
5. to foster and participate in affairs contributing to community services;
6. to promote the social and economic welfare of the nurse in the practice of her profession.[1]

While many nursing associations, designed to provide focal professional reference groups, have been plagued with low membership,[2] the CNA has been able to maintain a fairly high membership over the years. Many nursing associations, including the CNA, suffer from apathy of association members. Frequently, too, a lack of leadership is of concern to nursing associations. While the history of the CNA evidences some strong leadership patterns, the CNA is not entirely immune from the leadership concern. The possibility that nurses expect too much of their nursing leaders (i.e., they are often required to demonstrate clinical competence as well as leadership) has been raised by one author. She suggests that this expectation results in diffusion of energy and

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[1]Canadian Nurses' Association, "Letters, Patent, Bylaws, Rules and Regulations," (1972): 2.

[2]Glaser, p. 36.

failure to attend to significant priorities in nursing.[1] That this high expectation does not vary from expectations placed on leaders in other professions is very probable. In any case, nurses and nursing associations are often accused of assuming a posture of reaction rather than one of creating action or initiating action.

Bachand, in a study prepared for the Canadian Nurses' Association, suggests three roles for professional nursing associations: the protection of the public; the promotion of the profession and the professionals; and the protection and promotion of the socio-economic welfare of members.[2] While some of these roles necessarily overlap a clearer separation of these roles may assist associations to re-organize and take leadership as professionals with the patient as a prime beneficiary.

Increasing Systemic Relationships in Nursing

The model of nursing established by Florence Nightingale in England was quick to spread to North America. Glaser has documented the influence which Teachers' College of Columbia University had on modifying the Nightingale model to North America, and worldwide. Through its involvement in the ICN, by its involvement in United States foreign

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[1]Rose S. Le Roux, "Sex-Role Stereotyping and Leadership," Nursing Administration Quarterly 1 (Fall 1976): 25.

[2]Sr. Madeleine Bachand, "Project of a Comparative Study of Three Major Roles of the Professional Organization," Canadian Nurses Association, January 1972 (draft), p. 6.

aid programs, and through its policy of admitting foreign students, Teachers' College perpetuated a new model of nursing which stressed education over training. Only recently have some countries begun to adapt this model to their own needs.[1]

Canadian nursing has been influenced to a substantial degree by both English and American models of nursing and, to a lesser extent, by French nursing orders.

American nursing literature has had a great influence on the development of nursing in Canada.[2] Furthermore, in the absence of adequate training facilities not yet available in Canada, many Canadian nurses went to the United States to study, often returning to become leaders in establishing training schools and/or provincial nursing associations. Three of the Canadian nurses who remained in the United States became prominent leaders in American nursing, while continuing to influence Canadian nursing by maintaining contact with their Canadian colleagues.[3]

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[1]Glaser, pp. 12-22.

[2]Helen K. Mussallem, Nursing Education in Canada. A Study for the Royal Commission on Health Services (Ottawa: Queen's Printer, 1965): 7.

[3]Margaret M. Street, "Canadian Nursing in Perspective: Past, Present, Future." An address delivered on the occasion of the 50th Anniversary of The University of Alberta Hospital and The University of Alberta Schools of Nursing, November 15, 1975, pp. 6-7; The Leaf and the Lamp, p. 32. The three Canadian nurses who remained in the United States to become prominent in American nursing are Isabel Hampton-Robb, Adelaine Nutting, and Isabel Maitland Stewart.

Bureaucratization and Impersonalization

Selected problems of health professionals in bureaucracies have been discussed in chapter four. Of particular concern to nurses in the hospital setting (in addition to those problems already discussed) is the absence of a single line of authority in the bureaucracy. Nursing staff are required to take orders both from supervisors (the bureaucrats) and from the physicians (who are outside the bureaucratic chain of command). These dual lines of authority create difficulties of communication, discipline, and mechanisms for resolving problems, particularly at the ward level.[1] Each line of authority represents a separate though overlapping system, often with competing and conflicting demands. The bureaucratic system emphasizes the maintenance of the organization; the medical system emphasizes the provision of service.[2] Furthermore, the physicians, medical resident, and intern "function as individuals and are individually responsible for their actions" while the nurse is an "agent of the institution obligated to report and record" her activities.[3]

> The nurse, therefore, must handle physician-nurse conflicts by reporting through the proper channels, while the physician has free movement to approach the hospital administrator. This anomaly creates a dilemma for nursing in that it places the nurse in the position of being forced to use tact, flattery, or even subterfuge in her role of co-ordinator between a bureaucratic system and a free-wheeling artist.[4]

The head nurse's role on the nursing unit has been compared to that of a taxi dispatcher in her attempts to handle both the doctor's

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[1]Basil Georgopoulos and Floyd C. Mann, "The Hospital As Organization," in Patients, Physicians and Illness, ed. E. Garthy Jaco (New York: The Free Press, 1972): 309; Albert F. Wessen, "Hospital Ideology and Communication Between Ward Personnel," in Patients, Physicians and Illness, pp. 328-333.

[2]Kalisch and Kalisch, p. 54. [3]Mauksch, p. 113. [4]Ibid., pp. 130-131.

orders and administration demands.[1] In a sense, the nurse on the unit represents both the arm of administration, and the representative or delegate of the physician to the patient.[2] The nurse is expected to assume great responsibility for patient care and cure, but with limited authority from the organization or communication from the physician. In many cases it is the exception for nurses and physicians to visit patients together or even to discuss the patient's plan of care.[3]

> It is difficult to function as a deputy if the physician's medical intent as well as the contents of his conversation with the patient is [sic] not shared with the coordinator - the nurse.[4]

Davies suggests that in an attempt to cope with the demands of a dual authority system which demands increasing responsibility, nurses routinize tasks. These rules and routines protect nurses from the arbitrary whims of supervisors or doctors.[5]

While other health providers come and go, the nurse"comes and stays"on the unit. The consequence of remaining on the unit, added to the nurse's generalist knowledge, is that the coordinating function becomes the task of the nurse. Other specialists limit their responsibility to episodic activity, therefore it is the nurse who must fit together the parts of a whole. In fulfilling this coordinating, integrative role, the nurse represents not only nursing, but patient care.[6]

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[1]Katz, p. 60.

[2]Mauksch, p. 123.

[3]Kalisch and Kalisch, p. 53.

[4]Mauksch, pp. 136-137.

[5]Davies, p. 279.

[6]Mauksch, pp. 117-121.

Nightingale's notes describe this task:

> To be 'in charge' is certainly not only to carry out the proper measures yourself but to see that everyone else does so too; to see that no one either wilfully or ignorantly thwarts or prevents such measures; is neither to do everythink yourself nor to appoint a number of people to each duty, but to ensure that each does that duty to which he is appointed.[1]

Sometimes the "duty to which [one] is appointed" conflicts with professional values, and often both bureaucratic and professional values are in conflict with the best interests of the patient.[2] As nursing education has moved from the training model toward college and university education, the gap between the ideal and the real seems to have widened in patient care. Kramer maintains that defection of nurses from the profession, or nurses compromising their ideals, occurs when newly graduated nurses enter the bureaucracy and experience "role deprivation."[3] To correct this problem necessary changes would seem to involve greater cooperation between educators and service personnel in nursing,[4] and greater attention to "role models" in nursing practice.[5]

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[1]Nightingale, p. 24.

[2]Shirley M. Stinson, "Professionals in Bureaucracies," Nursing Papers 5 (December 1973): 16.

[3]Marlene Kramer, "Role Models, Role Conceptions, and Role Deprivation," Nursing Research 17 (March-April 1968): 116. "Role Deprivation" occurs when the nurse is deprived of enacting the role he perceives to be the role of nursing.

[4]Rachel Rotovich, "Internal Influences for Change on Nursing Service," in The Future is Now (New York: NLN, 1974): 38.

[5]Kramer, p. 119.

The effects of the bureaucracy on the patient, the recipient and consumer of care were brought to the attention of nurses in the early sixties in Esther Lucile Brown's Newer Dimensions of Patient Care.[1] The three volume series focused on the psychosocial aspects of patient care in general hospitals and represented one of the first of such explorations. In Part Two, Brown noted that

> . . . unless patients have a personal physician or a strong interested nursing supervisor to intercede for them, they are likely to find themselves unable to make effective requests.[2]

Brown also noted the "psychological stripping" that occurs as the patient enters the hospital bureaucracy.[3] The impersonalization and adherence to rules, regulations and routines are characteristic of bureaucracies and frequently cause nurses to forget or ignore the person who is their patient.

Transfer of Function to Profit Enterprise and Government

Nursing has felt the brunt of the transfer of health care function from that of a largely individual responsibility to profit enterprise and to government.

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[1]Esther Lucile Brown, Newer Dimensions of Patient Care (New York: Russell Sage Foundation) Part I. The Use of the Physical and Social Environment of the General Hospital for Therapeutic Purposes, 1961. Part II. Improving Staff Motivation and Competence in General Hospitals, 1962. Part III. Patients as People, 1964.

[2]Ibid., part II, p. 64.

[3]Brown, "Nursing and Patient Care," pp. 199-200.

> In the years during and following World War II, developments in Canadian society began to change the framework in which professional nurses work. Among these developments were the emerging patterns of government involvement in health services and the increasing proportion of registered nurses employed by hospitals.[1]

As governments have increasingly moved to identify and take responsibility for health care as a right, nurses, perhaps more than any other health providers, have moved to fill outstanding gaps in health care delivery to northern, rural and inner city areas.

Another main effect of the transfer of function has been experienced in recent years in the areas of nursing education and nursing licensure. Outstanding in Canada in the area of governmental control over nursing licensure are the Health Disciplines Act of Ontario, and the Professional Code of Quebec mentioned in chapter five. In regard to education, the recent Alberta Task Force on Nursing Education[2] commissioned by the Department of Advanced Education and Manpower in Alberta, is one cogent example of governmental interest and potential power in determining the future direction of nursing education in Alberta.

Urbanization and Suburbanization

> Nurses, like doctors conform in their general behaviour patterns to those of society in general. The fact of urbanization must be taken into account when rationalization

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[1] The Leaf and the Lamp, p. 8.

[2] The Alberta Task Force on Nursing Education by Walter H. Johns, Chairman. (Alberta: Advanced Education and Manpower, September 1975).

of health services and personnel are being considered.[1] While no numerical figures are available to accurately depict the rural-urban distribution of nurses, it is common knowledge that vacant nursing positions in rural areas are difficult to fill while urban centre nurses do not appear to be in short supply.[2]

In addition to discrepancies in distribution between urban and rural areas for basic health services provision, the urban-industrial setting gives rise to a set of problems to which health care in general and nursing care in particular must be prepared to respond.

> . . .[H]ealth services provide an important anchorage for individuals awash in an anomic sea. In responding to subjective needs, health services provide a refuge from the rigors of highly depersonalized living. . . . They are, in conjunction with social services, an adaptive mechanism for social survival and tension management, and comprise one of the more enlightened ways in which societies maintain themselves and survive.[3]

Changing Values

Two value changes which have had, and will continue to have, an impact on nursing are the changing roles of men and women in society,

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[1]Stanley Greenhill, Distribution of Available Health Care Personnel and Health Resources in Canada. A Commissioned Paper to the Community Health Centre Project (Toronto: Canadian Public Health Association): 9. Also see, An Abstract for Action, p. 35.

[2]Greenhill, p. 8.

[3]Roger M. Battisella and David B. Smith, "Toward a Definition of Health Services Management: A Humanist Orientation," International Journal of Health Services 4 (No. 4, 1974): 716.

and the changing value and belief system upon which nursing is based.

Women and Nursing

"The problems of women in general are reflected in the problems of nursing in particular."[1]

> I would earnestly ask my sisters to keep clear of both jargons now current everywhere. . . about the 'rights' of women which urges women to do all that men do, including the medical and other professions, merely because men do it and without regard to whether this is the best that women can do; and of the jargon which urges women to do nothing that men do, merely because they are women. . . . Surely woman should bring the best she has, whatever that is . . . without attending to either of these cries.[2]

This advice given by Nightingale suggests that the problem created by the fact that nursing is a woman's occupation in a male-dominated society, is not new. Roberts and Group document the separation of care and cure functions, and suggest that it is a story of men reducing women to the status of secondary healers.[3] They point out that while it is frequently assumed that within medicine there is one "long, unbroken line of male lineage," such is not the case. Historically, women were very involved in cure functions, and only in the founding of the medical associations were women denied that function and relegated the care function.[4] This action, by what evolved as a male medical profession, is seen by some as a move by physicians to retain physician dominance in health care since women, by their traditionally subordinate role in society, pose no threat to the physician who must

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[1]Le Roux, p. 28.

[2]Nightingale, p. 76.

[3]Roberts and Group, p. 304.

[4]Ibid., pp. 316-317.

be sure his subordinates stay subordinate.[1] Nightingale does not escape blame for her part in helping to establish surgeons (males) as superior to nurses in Scutari.[2]

A deference of women to men, then, appears to be part of a cultural norm which (some would hope) is now undergoing a change. Simpson and Simpson discuss the place of women in bureaucracies concluding that women more willingly submit to bureaucratic norms because of both this cultural norm and their family roles.[3] A woman's family role competes with her work role and usually results in a discontinuous and part-time career pattern.[4] Lamb deplores the discontinuity in career patterns so much a part of nursing, and suggests that the attitude that interruptions in career will be tolerated must be changed. Educating nurses is a costly proposition, therefore, she maintains, women who commit themselves to a nursing program must be committing themselves to an uninterrupted career.[5]

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[1]Carol A. Brown, "Women Workers in the Health Care Industry," International Journal of Health Services 5 (1975): 174.

[2]Bonnie Bullough, "Barriers to the Nurse Practitioner Movement: Problems of Women in a Woman's Field," International Journal of Health Services 5 (1975): 227. Nightingale refused to allow nurses to give any care to suffering men unless the surgeons ordered them to do so. Bullough suggests that this mechanism gained Nightingale and her 38 nurses the support of the army doctors but also helped establish the surgeon as superior to the nurse.

[3]Richard L. Simpson, and Ida H. Simpson, "Women and Bureaucracy in the Semi-Professions," in The Semi-Professions and Their Organizations, ed. Amitai Etzioni (New York: The Free Press, 1969): 197-199.

[4]Ibid., pp. 206-207.

[5]Karen T. Lamb, "Freedom for Our Sisters, Freedom for Ourselves," Nursing Forum 12 (1973): 341-343.

The pattern of recruitment and selection, as proposed by Lamb, would be a disservice to the patient. Glaser stated that in 1966, two-fifths of American hospital general-duty nurses were part-time workers, and noted that various sectors of the economy were adapting to the family as increasing numbers of women were returning to work.[1] Canadian nursing statistics from 1974 indicated that twenty eight per cent of the 118,897 nurses employed in nursing were working part-time.[2] While the number of part-time nurses creates problems of discontinuity and turnover (referred to by Stinson as "pathological tourism" and "pathological exit rates"[3]) the tremendous value of these nurses to nursing and to the patient would be hard to negate. Because of the increased opportunities for lay contact which part-time nurses generally have, they are frequently more attuned to lay-thinking. Such understanding and insight is a source of strength to the profession in dealing with the implementation of consumer rights in nursing. Greater efforts to stimulate their involvement in professional affairs, and well-planned utilization of this source of nursing personnel in patient care, would seem essential.

Values and Nursing

Warren has referred to values as the underlying principles according to which people make their choices.[4] In relation to consumer rights,

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[1]Glaser, p. 4.

[2]Canadian Nurses' Association, Countdown 1974 (Ottawa: Canadian Nurses' Association, 1975): 8.

[3]Stinson, "Deprofessionalization in Nursing?" p. 379.

[4]Warren, p. 85.

the key questions would seem to be, what are the basic underlying principles of choice in nursing? How do these affect rights of patients?

Glaser suggests that from the years when nursing was carried out largely by male and female religious orders, nurses valued the saving of lives, promotion of patient happiness and bringing spiritual guidance to patients. Such values required of the nurse dedication to long and hard work, low pay, and arduous and menial task. In the last century nursing has tended to seek education, efficiency, and pay equal to other occupations.[1] For some nurses there have been problems in reconciling collective bargaining with personal dedication and devotion, and the service ideal of a profession. Sometimes the emphasis on education may signify a value of "intellectual clarity as distinct from feelings and imagination."[2] Some nursing practitioners value technical and management skills, others value the provision of nursing service to patients and families.[3]

Wiedenbach encourages each nurse to examine her beliefs, and to ask herself, "What do I see as my unique responsibility in relation to the patient?" "How do I feel about people, their right to make decisions, their right to live, their ability to cope with demands made of them?" "How do I know how much help to give a patient, or how far to extend

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[1]Glaser, pp. 51-52.

[2]Rose Patricia McKay, "The Process of Theory Development in Nursing," (Ed.D. dissertation, Teachers' College, Columbia University, 1966), p. 63.

[3]Ibid., pp. 63-64.

myself in giving it?"[1] Amidst the changing values of society, the need for nurses to be able to answer these questions has never been greater.

Summary and Conclusions

Given the foregoing brief analysis of nursing, past and present, the following strengths and weaknesses which affect nursing's ability to be responsive to consumer rights are noted.

The often confusing array of staff involved in patient care, the inadequate doctor-nurse pattern of interaction, and a lack of clarity of purpose for professionalism are weaknesses. Strengths exist in the potential for nurses to use their abilities to provide individualized care for patients, to become involved in meaningful relationships with patients as a result of being freed from other specialty duties, and to specialize in patient advocacy.

The potential of an association of nurses, whether provincial or national, speaking with united voice to affect a changed attitude resulting in greater responsiveness to consumer rights both by nurses and other health care providers, should not be underestimated. On the other hand, the potential also exists for nursing associations to focus too heavily on socio-economic welfare issues for their members, to the detriment of concerns for quality of nursing practice and patients' rights issues, and respond too slowly to changing circumstances.

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[1]Ernestine Wiedenbach, Clinical Nursing - A Helping Art (New York: Springer Publishing Company, Inc., 1964), pp. 13-14.

The increased inter-communication and relationships with other countries may cause a professional group in one country to grasp a new idea without careful evaluation of its suitability to local needs. The possibility exists for Canadian health care leaders to implement a patient representative program, such as the one in the United States, without careful appraisal. Nurses may inadvertently support such action by inactivity. On the other hand, Canadian nurses could, by strong commitment to consumer rights in nursing, influence nurses and other health providers internationally to give priority to consumer rights in health care.

Impersonality, devotion to rules and routines, and increasing specialization are some of the hazards of hospitals, as bureaucracies, which interfere with patient rights. Further, the inability of newly-graduated nurses to reconcile the idealism of nursing education with the realism of the hospital, is a weakness. But the increasing verbal emphasis of the need for role models, creates the opportunity to move towards implementation of role models who could demonstrate consumer rights concerns in patient care to all staff.

The increasing involvement of government in the field of health care strengthens the potential for better health care for all consumers, but also increases the possibilities for consumer rights abuses by the introduction and maintenance of large systems for providing care.

The process of urbanization has created many problems associated with city living (e.g., anomie, increased stress, etc.) as well as problems of poor distirubtion of health services. But it also

creates the possibility and challenge for health care providers, including nurses, to fill a sustaining role, to give each consumer respect in care, and to plan for better utilization of all health providers.

The gradual removal of sex stereotyping, which at times has interfered with care to patients, can be a new strength in response to consumer rights. Possibly one of the greatest strengths for consumer rights will come as nurses are forced to look at their own values as those values relate to nursing. A re-assessment of values, in the face of consumer rights issues, will necessitate evaluation of the patient and his rights in the nursing care process.

CHAPTER 8

CONSUMER RIGHTS ELEMENTS IN NURSING: PAST AND PRESENT

The longstanding interest of nursing in consumer rights is noteworthy. Reflected in nursing literature over the years has been a concern, sometimes sporadic, with what was happening to the patient as a person. More recent nursing literature speaks directly of consumer/patient rights. Before reviewing the involvement of nurses in the four key areas of consumer rights, namely, the right to be informed, the right to be respected, the right to participate, and the right of equal access to health care,[1] the more tangible evidence of consumer rights concerns in nursing will be discussed briefly.

When the International Code of Nursing Ethics was adopted by the Grand Council of the International Council of Nurses in 1953, it included references to patient rights concerns. The preamble includes a statement which reads:

> Inherent in the code is the fundamental concept that the nurse believes in the essential freedoms of mankind and in the preservation of human life.[2]

Statements following this preamble include that of respect for the religious beliefs of a patient, and that nurses hold in confidence all personal information entrusted to them. The remaining twelve statements

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[1]"Consumer Rights in Health Care," Canadian Consumer 4:2 (April 1974): 1.

[2]"International Code of Nursing Ethics," Nursing Outlook 53:9 (September 1953): 1070.

contain more indirect reference to consumer rights concerns.[1]

Thirteen years before the American Hospital Association's statement on a Patient's Bill of Rights, the National League for Nursing drafted a Patient's Bill of Rights which later was entitled "What People Can Expect from a Modern Nursing Service."[2] Included in the document were three assumptions relating to nursing care and nursing personnel, plus seven statements relating to patient rights. These statements included the rights of confidentiality, respect, health education, participation, and access to continuity of care.

From the time an NLN committee was appointed in 1957 to draft a patient's bill of rights, until it was presented to the convention in 1959, some 3400 persons throughout the country (largely nurses) were involved in discussion of the draft. Initially the utility of such a document was seen as allowing for greater community participation in NLN activities. The discussion groups suggested broader usage of the bill to include its use as a teaching tool for student nurses and for inservice classes, a standard for judging the quality of patient care, an instrument to interpret nursing service to allied health professionals, and a topic for discussion purposes.[3] Little emphasis appears to have been directed to its use in consumer education.

Continued interest in a patient's bill of rights was evidenced in the attention accorded the AHA Patient's Bill of Rights in

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[1]Ibid.

[2]"Patient's Bill of Rights," Nursing Outlook 7 (June 1959): 364.

[3]Ibid.

nursing journals. Subsequently, various nursing associations have given consideration to consumer rights issues, and many have either drafted position papers, statements or bills,[1] or have moved to develop policy statements. In June of 1976, the Canadian Nurses' Association resolved:

> That CNA develop a policy statement on consumers' rights in health care using the Consumers' Association of Canada document 'Consumer Rights in Health Care' as a starting point for discussion.[2]

Recognizing that statements alone cannot guarantee patients' rights, what is nursing's record to date in relation to recognizing and effecting patients' rights?

Right to Be Informed

Nursing's early concern for consumer needs for health education is evident in the comments of two nursing leaders. Florence Nightingale deplored as one of the "coxcombries of education" that elements of astronomy are taught to every school child but laws which govern bodies and minds were unlearnt.[3] In 1913 Adelaide Nutting stated:

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[1]See for example, Alberta Association of Registered Nurses, "Position Paper on Nursing," Edmonton, 1975, which includes a statement on Patient Consumer Rights, "Nurses must respect and support consumer rights in health care: to be informed; to be respected as an individual with major responsibility for his own health care; right to participate in decision-making affecting his health; and right to equal access to health care regardless of the individual's economic status, sex, age, creed, ethnic origin and location." See also, "Patients' Nursing Care Rights Stated in Ohio," American Journal of Nursing 75 (July 1975): 112.

[2]"Resolutions Chart New Course for National Association in 1976-1978," Canadian Nurse 72 (August 1976): 32.

[3]Florence Nightingale, Notes on Nursing (London: Bookseller to the Queen, 1859), p. 7.

> Since the first condition of national well-being is that we should be healthy people, it may well seem strange that instruction in the vital subject of health has been so long excluded everywhere from our entire schema of education, formal and informal.[1]

Though a gradual trend to increase health education in the schools occurred, and while community health nurses have had some input into the health education process in schools,[2] health education of the general public has not always been considered important, nor have community or hospital nurses utilized health education opportunities fully.

A renewed interest in grasping health education opportunities is evident in the changing emphasis in health care encouraged by Lalonde,

> The [nurse's] goal will be to ensure that . . . people will be brought to understand their physiology, that they obtain information on the importance of healthy lifestyle, especially physical activity and nutrition.[3]

For consumers within health organizations, the right to be informed calls for further information and education. Nightingale advised that uncertainty created by withholding information from the patient could be damaging to him and suggested that if the patient was

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[1]Adelaide Nutting, "The Nurse as Educator," American Journal of Nursing 13 (1912-1913): 928.

[2]Ruth Freeman, Community Health Nursing Practice (Toronto: W.B. Saunders Company, 1970), pp. 316-317.

[3]National Conference on Nurses for Community Service (Ottawa: Department of National Health and Welfare and The Canadian Nurses' Association, 1973): 105.

strong enough to undergo surgery, he was strong enough to accept information about the expected outcome.[1] To the detriment of patient-rights, the influence of medical directive in matters of information-giving was felt strongly by nurses at the turn of the century, as exemplified in the following advice given by a doctor to a young nurse in 1904.

> Never try to explain to patients their affliction; don't inform them as to variations in temperature and pulse, and add to it your opinion as to improvement or the reverse; you spoil the disposition of our patients in every case. Leave the judgement of the condition of the case entirely to us physicians.[2]

This type of influence continues to persist and is a factor which is directly related to problems in doctor-nurse relationships. In addition, it should be emphasized that nurses may tend to hide behind this type of advice out of a sense of their own inadequacy.[3]

In the sixties, several studies were conducted attempting to discover what patients need to know and want to know.[4] One particular study focused on what the patient asks or says, and revealed that in few instances does the patient actually say what he means.[5] For example,

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[1]Nightingale, p. 26.

[2]Antoine Boettcher, "How Can We Improve the Disposition of Our Patients and Gain Their Confidence? - A Story," American Journal of Nursing 5 (December 1904): 169.

[3]Joan S. Dodge, "Nurses' Sense of Adequacy and Attitudes Toward Keeping Patients Informed," in Social Interaction and Patient Care, p. 88. Ed. by James K. Skipper and Robert C. Leonard (Toronto: J.B. Lippincott Co., 1965).

[4]For example see Alice Dloughy, "What Patients Want to Know About their Diagnostic Tests?" Nursing Outlook 11 (April 1963): 265-267; Dorothy Linehan, "What Does the Patient Want to Know?" American Journal of Nursing 66 (May 1966): 1066-1070.

[5]Ruth Elder, "What is the Patient Saying?" Nursing Forum 11 (1963): 25-37.

> . . . the patient who asks the nurse what his temperature might be not only may inquire about the severity of his illness but indirectly may also ask: 'To what services am I entitled today?' Hospital rules which prevent the nurse from giving such information may deny the patient guidelines for the rules applicable to his behaviour.[1]

Additional studies conducted in the seventies have reiterated the need for nurses to be sensitive to the type and amount of patient need for information.[2] From the moment the patient enters the hospital door he has a right to information about what is happening to him; and nurses must discern how, when, and what to tell him.[3] The patient must also be told what is expected of him in the situation.[4]

Patients come to hospital with a variety of information bases. The patient's ignorance of hospital rules forces his dependence upon prior learning, either direct or indirect, of the patient's role.[5] Patients draw on these experiences in different ways, making the health team's input of information, which can relieve uncertainties, of vital importance.[6]

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[1]Daisy L. Tagliacozzo and Hans O. Mauksch, "The Patient's View of the Patient's Role," in Patients, Physicians, and Illness, 2nd edition, p. 176. Edited by E. Garthy Jaco (New York: The Free Press, 1972).

[2]For example, see J. Marks and M. Clarke, "The Hospital Patient and His Knowledge of the Drugs He is Receiving," International Nursing Review 19:1 (1972): 39-51; Joan S. Dodge, "What Patients Should Be Told: Patients' and Nurses' Belief," American Journal of Nursing 72:10 (October 1972): 1852-1854.

[3]Carolyn Stockwell and Jeanette Tada, "The Right to Know," Canadian Nurse 72:11 (November 1976): 22.

[4]Victoria Thomas, "Your Patient Is No Moron," RN 29:1 (January 1966): 64.

[5]Tagliacozzo and Mauksch, p. 172.

[6]Leola A. Robinson, "Patients Information Base: A Key To Care," Canadian Nurse 70:12 (December 1974): 34-36.

Issues surrounding informed consent involve nurses deeply. Adherence to the dictum that what is best for the patient is an issue which only he can determine, has been urged.[1] Nurses have also been reminded to be alert to signs that the patient needs further clarification following medical explanations, and to be ready to pay the "price of medical and administrative displeasure" if at any time the nurse feels the patient has been coerced into consent.[2]

Right to Be Respected

A genuine respect for those who are sick or suffering was advocated by Nightingale who urged nurses to understand the sick person and accept his behaviour non-judgementally.[3] A respect for the rights of people "to continue to perform as they have been and to resist" attempts at change has been advocated by McGrath in relation to community nurses, but applies to all nurses.[4] Thorner maintains that this same respect must be accorded to mentally ill patients in respecting, for example, their right to refuse medications.[5]

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[1]Beatrice J. Kalisch, "Of Half-Gods and Mortals: Aesulapian Authority," Nursing Outlook 23:1 (January 1975): 25.

[2]Lucie Young Kelly, "The Patient's Right to Know," Nursing Outlook 24:1 (January 1976): 28-32.

[3]Nightingale, p. 35.

[4]Eileen M. McGrath, "Guidelines to New Community Workers," Nursing Outlook 19:7 (July 1971): 480.

[5]Nancy Thorner, "Nurses Violate Their Patient's Rights," Journal of Psychiatric Nursing and Mental Health Services 14:1 (January 1976): 7-12.

Nightingale also stated that every nurse must be one who can be depended upon, who is capable of being a "confidential" nurse, who is "no gossip or vain talker," and who would only answer questions about her sick to those who have a right to ask.[1] While the patient role requires some invasion of privacy, Smith sees the nurse's role as one of lessening embarrassment, being sensitive to what is confidential, arranging for patient privacy, and protecting the vulnerable.[2]

Protection of the rights of patients in research has been a subject of increasing concern to nurses since the late sixties. Good points out the fact that "there are more statutory laws in the provinces of Canada for the protection of research animals than for people."[3] Abdellah articulates this concern, urging action for greater human protection.[4] In 1968, the A.N.A. issued guidelines for nursing research,[5] and in 1969 the editorial advisory committee of Nursing Research established a policy regarding the nature of research involving human subjects.[6] In 1972, the CNA Directors outlined a document

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[1]Nightingale, p. 70.

[2]Dorothy Smith, "Patienthood and Its Threat to Privacy," American Journal of Nursing 69:3 (March 1969): 510-513.

[3]Shirley R. Good, "The Ethics of Nursing Research," in Contemporary Issues in Canadian Law for Nurses, p. 166. Edited by Shirley R. Good and Janet C. Kerr (Toronto: Holt, Rinehart and Winston of Canada Ltd., 1973).

[4]Faye Abdellah, "Protecting the Rights of Human Subjects," Nursing Research 16:4 (Fall 1967): 316-320.

[5]"The Nurse in Research: A.N.A. Guidelines on Ethical Values," Nursing Research 17:2 (March-April 1968): 104-107.

[6]Lucille E. Notter, "Protecting the Rights of the Research Subjects," Nursing Research 18:6 (November-December 1969): 483.

on ethics for nursing research which included rights of the subjects and responsibilities of the researcher.[1]

Berthold cautions that while the value conflicts in research can be codified, the issues are clouded with ambiguity and require thorough debate and discussion. Central concerns with regard to the patient are seen to be invasion of privacy, time and energy requirements, loss of dignity or autonomy, mental or physical pain and discomfort, and risk of physical and emotional injury.[2] The issue of informed consent in nursing research becomes highly complex in terms of assessing both the knowledgement requirement of the patient and his competency to make decisions.[3] Berthold therefore urges nurses to take the full responsibility of maintaining legal and moral rights in nursing research.[4] "Ethical guidelines cannot be legally enforced and adherence to the principles set forth is the responsibility of each individual researcher."[5]

Right to Participate

> And what nursing has to do in either case, is to put the patient in the best condition for nature to act on him.[6]

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[1]"Ethics of Nursing Research," Canadian Nurse 68:9 (September 1972): 23-25.

[2]Jeanne Saylor Berthold, "Advancement of Science and Technology While Maintaining Human Rights and Values," Nursing Research 18:6 (November-December 1969): 517.

[3]Ibid., pp. 517-518; see also Good, pp. 168-169.

[4]Berthold, p. 519.

[5]Good, p. 167.

[6]Nightingale, p. 75.

While some nurses have interpreted Nightingale's dictum as implying a passive role for the patient, others see "the best condition" as inclusive of an assessment of the patient's willingness and ability to be involved in his care. Nurses have long held to a belief in "total patient care," but perhaps this description has connotations which are not in the best interests of the patient in that total care is frequently taken to imply a completely helpless patient served by a nurse who must do everything for him including his problem-solving.[1]

> Despite all the fine words that have been written about nurses encouraging the patient to participate in decisions about his care, the mother (or father) figure still comes on pretty strong in most nurses; many times they make the decision for the patient.[2]

The patient's participation in his own care by involvement in planning for his care and possible recovery, enables him to assume some responsibility for the effect of that care.[3] Poole suggests that patient involvement in care through nurse-patient collaboration could help to put the "caring" back into nursing care.[4] Involvement of both patient and family in the nursing care plan creates a climate for growth and learning rather than "conspiratorial manipulation."[5] McGilloway

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[1]Karyl K. Blair, "It's the Patient's Problem -- and Decision," Nursing Outlook 19:9 (September 1971): 589.

[2]"The Health Care Consumer: Compliant Captive?" Nursing Outlook 23:1 (January 1975): 21.

[3]Phyllis Tyron, "Patient Participation vs. Patient Passivity," Nursing Forum 2:2 (1963): 56-57; Christian A. Hovde, "The Need for Participation," Occupational Health Nursing 18:11 (November 1970): 10.

[4]Pam Poole, "Nurse, Please Show Me That You Care!" Canadian Nurse 66:2 (February 1970): 27.

[5]Marlene Kramer, "Standard 4 - Nursing Care Plans. . . Power to the Patient," Journal of Nursing Administration 2:5 (September-October 1972): 33-34.

reminds nurses that they are unavoidably involved in the affairs of the patient to a significant degree because of the patient's dependency which often makes rational judgement difficult for him.[1] Nurses are cautioned to make "keen assessments" as to the patient's needs and capabilities in dealing with his own care.[2,3]

Consumer input in the form of evaluation of nursing care has been given serious attention by nurses in the past two decades.[4] Nehring and Geach describe consumer evaluation as the most valuable information input for assessing nursing practice.[5] They further suggest, however, that obtaining this information from patients is difficult because fear of reprisal prevents patients from commenting negatively on their care.[6] Kirchkoff reports that nurses were surprised that

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[1]F.A. McGilloway, "Dependence and Vulnerability in the Nurse/Patient Situation," Journal of Advanced Nursing 1 (May 1976): 229, 235.

[2]Kalisch, p. 25; Ann T. Salinsky and Vivan Romoff, "Consumer Participation," Journal of Nursing Administration 2 (May-June 1972): 16.

[3]Bernadet M. Ratsoy, "Maternity Patients Make Decision," Canadian Nurse 70 (April 1974): 42-44. An example of participation in care is operative in a Vancouver hospital where maternity patients are recognized as willing to assume responsibility and capable of making decisions.

[4]For example, Gladys E. Post, "Opinion Survey Questionnaire," Hospital Management 84 (December 1957): 46-47; Christine Smith, "We Asked the Patients," Nursing Outlook 6 (August 1958): 458-459; Winnifred Raphael, "Do We Know What Our Patients Think? A Survey Comparing the View of Patients, Staff and Committee Members," International Journal of Nursing Studies 4 (1967): 209-223.

[5]Virginia Nehring and Barbara Geach, "Patients' Evaluation of Their Care - Why They Don't Complain," Nursing Outlook 21 (May 1973): 321.

[6]Ibid., p. 317.

patients, recently transferred from the intensive care unit, were so perceptive of the nursing care problems in their evaluation of care.[1] This attitude supports the view that the professional believes that he, not the consumer, is the best judge of services rendered.[2] If nurses are serious about becoming more accountable to the patient, they must continue to extend to the patient and the family opportunities to evaluate nursing care.[3] Outcomes of such evaluation could be better nursing care, increased job satisfaction, and consumer satisfaction with the interest of the professional in hearing his opinion.[4]

Consumer participation in planning and evaluating health services and nursing on a broader scale is not new to nursing. The NLN has always involved consumers in its organization. As far back as 1957, Freeman was urging the League to allow greater citizen participation by defining the relative responsibilities of the nurses and the non-nurses within the League, as well as to determine the type and amount of lay members needed and how to get and keep members. In addition, she urged that lay members be trained for the job.[5] Ujhely suggested that

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[1]Karin T. Kirchkoff, "Let's Ask the Patient: Consumer Input Can Improve Patient Care," Journal of Nursing Administration 6 (December 1976): 39.

[2]Gwen D. Marram, "Patients' Evaluation of Their Care - Importance to the Nurse," Nursing Outlook 21 (May 1973): 323-324.

[3]Ibid., p. 324.

[4]Kirchkoff, p. 40.

[5]Ruth Freeman, "Meeting Nursing Needs Through Citizen Participation," Nursing Outlook 5 (January 1957): 43-44; Ruth Freeman, "Community Action - Key to Better Nursing Care," Nursing Outlook 9 (December 1961): 748.

nurses must see the patient/consumer as an equal partner not only in the patient-nurse relationship but in community health planning as well.[1] To effect such consumer involvement, nurses need practice in nurse-consumer dialogue, and an appreciation for the potential resource the consumer might offer to the problems facing nursing today.[2] Since the consumer bears the major cost of both the education of health care providers and the cost of health care, consumer representation on boards or councils of professional associations might be a reasonable step to allow for greater public input into the governing of the professions, including the nursing profession.[3] At the same time, nurses must be mindful that any type of consumer participation is neither desirable nor undesirable in itself, but only if it benefits the consumer.

Right to Equal Access to Care

The consumer's lack of first-line access to health professionals other than physicians is a structural problem since the physician retains the function of gatekeeper in health care.[4] While the family doctor model is still considered the "ideal" model of medical care by most consumers, the realities of specialization and the subsequent necessity

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[1]Ujhely, pp. 22-23.

[2]Lowell S. Levin, "Time to Hear a Different Drum," American Journal of Nursing 72 (November 1972): 2010.

[3]Audrey Thompson, "Projections: Specialty Nursing," in National Conference on Nurses for Community Service, p. 46.

[4]Heken Nakagawa, "The Social Organization of Health Care and the Myth of Free Choice," in Health Care Issues, p. 83. Edited by Madeleine Leininger (Philadelphia, Pa.: F.A. Davis Co., 1974).

of a team approach to care has made that model obsolete.[1]

> One critical human requirement, a deficit arising from the loss of intimate community relationships, is to develop a social structure which formally organizes a group of professionals to fill a sustaining role.[2]

Leininger has proposed a model of health care in which the consumer would have "prompt and ready access to care through a variety of routes."[3] Such a system would offer the consumer a choice of services from the variety of health disciplines based on his needs and not confined to physician services only at the point of entry. Professional nurses, who are the largest health manpower group, would move into the "health preventative subsystem" and "assume greater responsibility for health practices in the restorative system." While nurses would assume greater responsibility for primary care, they would also continue their responsibilities in the care of the chronically ill.[4]

The National Commission for the Study of Nursing and Nursing Education questioned whether the health care system could afford not utilizing the largest group of health professionals (nurses) at anything less than highest capacity as long as access to care was unequal.[5] One

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[1] An Abstract for Action. National Commission for the Study of Nursing and Nursing Education, Jerome P. Lysaught, Director (Toronto: McGraw-Hill Book Co., 1970): 11.

[2] Nakagawa, p. 82.

[3] Madeleine Leininger, "An Open Health Care System Model," Nursing Outlook 21 (March 1973): 171.

[4] Ibid., p. 175.

[5] An Abstract for Action, pp. 27-28.

nurse suggests that a valuable nursing contribution can be made to the nation's health by the nurse practitioner model.[1]

Implications for Nursing

> In reality I see the possibility of a system which exists to help the client or consumer. There will be opportunities for most of us who are now nurses to find a place in the system. But as the system develops those who are called nurses will care for people and those who manipulate machines that monitor people will be called something else. . . . And the biggest change of all is that the needs of people will take precedence over the needs of the provider.[2]

The option is still available for nurses to become part of a consumer-oriented system. But in order to undertake that option, resolution of many related problems which have plagued nursing through the years must be found. Somewhere in the debate over care or cure, handmaiden or independent practitioner, and division of nursing tasks, nurses have almost lost the patient - the very reason to be.

In one respect, the advent of the patient representative might symbolize to nurses a colossal failure on their part to adequately protect patient rights. If, as Mauksch has described, the nurse is that uniting and remaining element left, when all the specialists have carved out their piece of patient care which once belonged to the

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[1]Marion C. Ferguson, "Nursing at the Crossroads. Which Way To Turn? A Look at the Model of the Nurse Practitioner," Journal of Advanced Nursing 1 (May 1976): 237-242.

[2]Pamela E. Poole, "Projections: A National View," in National Conference on Nurses for Community Service, p. 35.

nurse,[1] what significant remnant is there for nursing if a new specialist carves out the function of representing the patient?

Several nurses have stressed the role of the nurse as patient advocate amidst changing patterns of health care. Advances in medical treatment creating earlier ambulation of patients changed the image of the nurse somewhat from bedside nursing to "patient-side" nursing.[2]

> The nature of nursing implies that the nurse is the patient's advocate and her distinctive relationships with the patient provide opportunities for patient assessment with and for the patient that are beyond the realm of those providing intermittant therapy for one functional disorder or disability.[3]

Annas suggests that while the nurse is in the position of day-to-day, hour-to-hour care conducive to an effective patient advocacy function, forces in the health care organization discourage her from taking an activist role. Therefore, he maintains that a patient advocate with wide-reaching powers is necessary. The broad power he envisions includes: access to medical records, access to chiefs of all services, access to all patient support services, ability to call in qualified consultants, ability to delay discharge, freedom to lodge a complaint against any director, and freedom to monitor hospital committees.[4]

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[1]Hans O. Mauksch, "The Organizational Context of Nursing Practice," in The Nursing Profession, ed. Fred Davis (New York: John Wiley and Sons, Inc., 1966): 124.

[2]"In the Patient's Behalf," Nursing Outlook 8 (June 1960): 303.

[3]Eleanor C. Lambertsen, "Knowing Roles Aids Doctor-Nurse Accord," Modern Hospital 112 (January 1969): 77.

[4]George J. Annas, "The Patient Rights Advocate: Can Nurses Effectively Fill This Role?" Supervisor Nurse 5 (July 1974): 20, 23-24.

This proposed advocate would, in effect, have far greater powers than the average nurse or the average patient representative described in chapter six. Annas envisions a role for nurses as advocates if they are given special training[1] and, the writer would add, legitimation.

Perhaps the bureaucracy has grown to such a degree that nurses, caught in the hierarchal chain of the nursing department are not able and/or see themselves as not able, to cross the channels to get at the sources of patients' concerns. Perhaps the general introduction of patient advocates would cause nurses to abandon their advocacy roles entirely. But a patient representative with wide powers might assist nurses greatly to develop their advocacy function. The point is, if a new worker is needed, at least it should be made clear as to why he or she is needed.

Inevitably, much of the problem of truly representing a patient and caring for a patient stems from the conflicts provoked by the inadequate doctor-nurse relationship. Tagliacozzo and Mauksch note the dilemma the patient experiences when he must cope with the strain of conflicting demands and expectations of the doctor and the nurse. Patients feel the uncertainties of poor communication and frequently are caught in the position of having "to function as interpreter and intermediary between these two all important functionaries."[2]

Gilchrist suggests that health professionals must become more

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[1]Ibid., p. 25.

[2]Tagliacozzo and Mauksch, p. 173, 184.

interdependent and accountable.[1] The public will no longer tolerate "our sparring with each other to build our own individual empires."[2] Adequate numbers of effective physician-nurse team models based on collaborative and collegial relationships are needed to halt the perpetuations of the present inadequate relationship.[3] Christman insists that organizational change must precede attitudinal change since the student is coopted by the doctor-nurse model she sees in operation presently.[4] Nurses who are willing to work with patients and with persons from various professional groups to alter structures and practices of institutions are seen as essential.[5]

In addition to doctor-nurse conflicts, conflicting relationships among professional and non-professional staff on the nursing unit based on division of nursing tasks must be resolved.

> Role conflict makes the work environment of the nurse uncomfortable but this is not the most important consideration. The most important aspect of the tension production is its effect on the patient. . . . If the conflict level is high

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[1]Joan M. Gilchrist, "The Nature of Nursing in the Health Care Structure," Nursing Papers 5 (December 1973): 13.

[2]"Patient Rights, Nursing Responsibilities," Hospitals, J.A.H.A. 47 (June 16, 1973): 102.

[3]Robert A. Hoekelman, "Nurse-Physician Relationships," American Journal of Nursing 75 (July 1975): 1152.

[4]"Pre-requisite for Nurse-Physician Collaboration: Nursing Autonomy," Nursing Administration Quarterly 1 (Fall 1976): 61.

[5]Anne Cronin Mosey, "Meeting Health Needs," Nursing Digest 2 (May-June 1974): 95-96.

> among the personnel of a ward the tensions are communicated to the patient and will affect his recovery.[1]

Nurses need to question, and speak out individually and collectively about the quality of care. Too many nurses continue to succumb to the advice that "no prudent nurse will discuss physicians or criticize their methods."[2]

> To raise questions about the quality of care is a bad thing for a nurse to do. To keep quiet about it is a good thing. That's how the ethics fall down.[3]

Reaction to a recent survey on nursing opinions regarding the quality of care provided in their respective institutions reflects this attitude of the "badness" of nurses who speak out.[4]

To date the voice of nursing has been "sadly muted at a level where policies and decisions which govern the provision of health care are made."[5] While this is an odd circumstance for a profession most closely associated with the people and their health, it has occurred because many nurses consider political action unprofessional, unwomanly, and unnecessary.[6] Mussallem argues that nurses must seek representation

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[1]Neil Warren Rheiner, "The Role and Status of Nursing as Perceived by Nurses," (Ph.D. dissertation, University of Nebraska, 1970): 34-35.

[2]Catherine Moriarty, "Where the Nurse Sometimes Fails," American Journal of Nursing 15 (November 1914): 113.

[3]"Nader Group Plans Manual for Hospital Workers," Modern Hospital 120 (June 1973): 26.

[4]"How Nurses Rate Hospital Care," Time, January 17, 1977.

[5]Helen K. Mussallem, "The Nurse's Role in Policy-Making and Planning," International Nursing Review 20 (1973): 10.

[6]Marjorie Stanton, "Political Action and Nursing," Nursing Clinics of North America 9 (September 1974): 579-581.

on planning bodies and encourage formal cooperation between professional associations and government agencies.[1] Nurses cannot continue to wait to react to issues, but must be prepared to commit themselves publicly to their beliefs about nursing, health, and society.[2] Opinions, based on sound conclusions, must be offered in the right place at the right time.[3] The professional association must be able to serve as a pressure group to allow nurses to bring pressure on governments and other groups.[4]

Basic to political action in the area of consumer rights is the matter of education of nurses about consumer rights. Nursing service departments, continuing education programs, nursing education programs and nursing associations must promote a greater understanding of patient rights.[5] Rozovsky urges three alternatives to the patient's bill of rights as a means of improving care, namely, 1) that legal education become part of the curriculum of all health occupations, 2) that attempts be directed toward creating a spirit of responsiveness in all hospital personnel, and 3) that boards assume greater responsibility in establishing auditing systems for medical, nursing and technical care.[6]

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[1]"Canadian Association's Executive Director Has Advice for Associations," International Nursing Review 21:1 (1974): 4. Note: The Executive Director of the CNA is a member of a joint committee of the CHA, the CNA and the CMA which meets periodically to discuss issues of common concern such as the Patient's Bill of Rights, ethical aspects of life-saving measures, etc. See "A Report to the Membership," Canadian Nurse 72 (August 1976): 30.

[2]Stanton, p. 584. [3]Mussallem, p. 11.

[4]Glennis Zilm, "Nursing Associations - Are They Coming or Going?" Canadian Nurse 65 (September 1969): 35.

[5]Thorner, pp. 11-12.

[6]Lorne Elkin Rozovsky, "A Canadian Patient's Bill of Rights," Dimensions in Health Service 51 (December 1974): 10.

Liberal education, and use of literature written by consumers of care (about their care) is seen as one route towards sensitization of nurses to patient needs and rights.[1] Continuing education is seen as another way to bring some assurance of quality care to the consumer.[2] Since patients are not in a position to judge the competencies of those who care for them,[3] nurses must be responsible to maintain competence and to undergo self-examination in the form of nursing audits.

In the process of self-examination, nurses must examine their values and their caring. Ashley charges that nursing values have been distorted by misuse of their power to support the physician rather than the patient.[4] Hayter emphasizes that caring involves a sensitive human dimension, and also involves finding out "what is and is not helpful in nursing care." She suggests that the most promising way to find out is through nursing research.[5] Labelle challenges nurses to show that good nursing care makes a difference.[6]

Nurses need to carefully assess organizational structures and

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[1]M.A. Ruffing, "Literature by Consumers," Nursing Forum 14 (1975): 87-93.

[2]Erline Perkins McGriff, Accountability to the Consumer Through Continuing Education in Nursing (New York: National League of Nursing, 1974).

[3]Tagliacozzo, p. 182.

[4]Joanne Ashley, "About Power in Nursing," Nursing Outlook 21 (October 1973): 64.

[5]Jean Hayter, "What Does Caring Really Mean?" Canadian Nurse 62 (October 1966): 31.

[6]"A Retrospective Assessment," Canadian Nurse 72 (August 1976): 27.

practices to "ensure that inertia and tradition do not perpetuate the use of professional personnel for non-nursing tasks."[1] A realization that the actual image of nursing is a careful blending of supportive personal concern with technical competence is important.[2]

Nursing's future depends upon the ability of nurses to enhance their self-worth, to work together, and to plan their future together. Nurses need to examine change, and promote it when desirable.[3] The fear of being too aggressive must be weighted in the balance against the potential contributions to be made to the profession and the work of the profession.[4] It would seem logical to expect that among these potential contributions is the contribution nurses could make to consumer rights, regardless of the underlying motivation:

> . . . most nurses place a high value on helping people. Perhaps nurses who might not develop professional autonomy for self-serving reasons will do so if they can be shown that their patients will benefit significantly. Perhaps some nurses will change when they realize that there are some dramatic discrepancies among their most cherished values.[5]

Nurses may take at least three stances in relation to consumer rights in nursing. They may disclaim any responsibility and take no

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[1]An Abstract for Action, p. 93.

[2]Olive W. Simpson and Yvonne N. Green, "Androgynous Nurse," Canadian Nurse 71 (December 1975): 20-21.

[3]Ingeborg Mauksch, "The Future is Now," in The Future is Now (New York: National League of Nursing, 1974), p. 8.

[4]Mussallem, p. 11.

[5]Loren Pankratz and Deanna Pankratz, Journal of Health and Social Behaviour 15 (September 1974): 212.

action whatsoever to implement consumer rights. They may claim some responsibility and take action to see that provisions are made by others for consumer rights in health care and in nursing. Or, nurses may claim substantial responsibility and develop strategies to implement consumer rights in nursing and in health care generally. In doing so, nurses may take on the patient representative function as part of their role and function.

The effect on the consumer/patient if the first stance is taken would be highly detrimental. If either of the second two stances are taken, consumer rights in health care and in nursing might be realized, and the consumer stands to gain. However, it is the writer's thesis that nursing stands to lose its "raison d'etre" unless substantial responsibility for consumer rights implementation in nursing is taken by nurses. Because nurses constitute the largest body of health care providers, because they are attuned to total patient care, and because they have extensive direct contact with patients and patients' families, the potential for nurses to implement consumer rights in health care is greater than for any other provider of care. Consequently, even the consumer stands to gain from this approach to a greater degree.

PART V

CONCLUSION

CHAPTER 9

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

Consumer rights must be examined within the context of societal, and subsequent health care organizational, change. Seven major changes have occurred within communities over the past decades which are reflected in society at large.[1]

Firstly, a division of labor has resulted in specialization and subspecialization requiring a highly complex interdependency of function. Yet, the experience of the worker is one of isolation in his highly specialized knowledge or skill directed to a limited function. Secondly, differentiation of interests and associations has resulted in relationships with people quite apart from those interests stimulated by a common locale.

A third change has been that decisions once made in the local community are now made, or at least strongly influenced, by persons often far removed from the local scene, as communities experience increasing systemic relationships to the larger society. Growth of organizations in size and in complexity, resulting in a situation of increased bureaucratization, which frequently has as its byproduct depersonalization, constitutes a fourth significant change.

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[1]Roland L. Warren, The Community in America, 2nd edition (Chicago: Rand McNally and Co., 1972).

Another major change has been that functions once performed by families or neighbors are increasingly being transferred to profit enterprise and government. Sixthly, growth of cities and their surrounding suburbs has given rise to a variety of complex urban problems. Lastly, changing values are evident. An increasing acceptance of governmental activity as positive, change from a moral to a causal explanation for human behaviour, change that stresses a planning approach as opposed to a moral approach to social problems, and a growing distrust of professional and institutional authority, are some of the more significant value changes.

While these major changes overlap, one over-riding effect of community/societal change has been the loss of control which the individual experiences over his own situation. Increasing concern for individual rights seem to have coincided with this growing loss of control.

Three major efforts have been directed at rectifying the imbalance. Predominant in these efforts are the human rights affirmations and bills of rights stimulated by the Universal Declaration of Human Rights. The Canadian Bill of Rights, for example, expresses the concern of Canadian people for human rights, and the emergence of the provincial legislative ombudsman offices, demonstrates a willingness on the part of Canadians to "put some teeth" into the various provincial bills of rights.

A resurgence of consumerism has been another attempt at regaining some consumer control. The new consumerism in the general population appears to be a product of: a loss of faith in the respon-

siveness of corporate institutions; rising education levels and rising expectations; and higher incomes and general affluence. Community development, while admittedly a minor effort (in terms of numbers of consumers involved, not in terms of its philosophical base), has assisted some consumers in their attempts to regain control of their local community.

Societal changes have not bypassed health professionals and health care organizations. Specialization and subspecialization have produced a division of labor far remote from the doctor-nurse team of the past. Professionalism plays a leading role within the health care structure, and the results of the professional dominance of medicine have had far-reaching implications, particularly in relation to the perpetuation of outmoded models of health care.

Influence of professional associations and unions on their members tends to maintain the present systems of care, often in the interests of the providers. Linkages of local associations and unions to their national and international counterparts produces a cosmopolitan effect on members.

Growth of hospitals as bureaucracies provides potentially efficient means for task accomplishment, but also creates problems of professional-bureaucratic conflict and depersonalization of patient care. A transfer of health care functions, particularly to government, has occurred concomitant with an increasing valuation of health, and a feeling that health care is a basic human right. Rising expectations and rising costs have moved some governments to an increased emphasis on

consumer responsibility for personal health promotion - thus a transfer of responsibility back to the individual and the community, but with little or no authority to act on that responsibility.

Urbanization and suburbanization have resulted in problems of distribution of health personnel and services. Rural populations tend to experience poorer access to care. Various attempts to distribute services more equitably have been made, including the present emphasis on regionalization of health services. The increasing value placed on health, and the erosion of professional authority, have placed unprecedented strains on the health care system.

There has been some confusion among three rights related to health and health care, namely, health as a right, the right to health care, and the right to be sick.[1] Among the concerns of the new consumerism are rights in health care as well as rights to health care. In an attempt to rectify violations of patient/consumer rights, malpractise suits against professionals have increased.

The American Hospital Association's statement on a Patient's Bill of Rights, affirmed in 1972, has been viewed by many as a milestone in consumer rights in health care. Significant among the plethora of patient's bills of rights issued since 1972, is the bill of the Consumer Association of Canada, entitled "Consumer Rights in Health Care." While skepticism about the effect of such statements, documents, or bills prevails, the educative effect for consumers and health care

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[1]Charles Fried, "Rights and Health Care - Beyond Equity and Efficiency," New England Journal of Medicine 293 (1975): 241-245.

providers cannot be negated.

The consumer's right to be informed includes not only the right to health education, but also the right to information about the health care system, about his own care, and about the expectations placed on him as the consumer of care. Informed consent becomes a complex and highly problematic area of concern. The right of confidentiality and the right to refuse treatment are the major foci of the consumer's right to be respected. The right to die and rights of the mentally ill complicate the ease of assurance of these rights, and emphasize the need for a broader societal input into these ethical decisions.

The right to participate in decision-making includes decision-making in matters of personal care, as well as in the planning and evaluation of health care services. Issues of consumer participation in planning and evaluation include questions as to the type of participation, the reason for participation, the choice of representatives, and the means of effective participation.

The right to equal access to health care implies that all persons should have a fair portion of the available resource for health care. Underserviced areas, and concern for professional competence are central issues of consumer concern in this area.

Increase in numbers of patient representatives as a means of effecting consumer rights in health care has occurred primarily as an offshoot of hospital public relations concerns, and laterally as an imitation of the legislative ombudsman office. Striking similarities exist in role and function of the patient representative and the legis-

lative ombudsman.

Largely because of nursing's "day-to-day, hour-to-hour" involvement with the patient, and nursing's attention to total patient care, the function of patient representative, ombudsman, or advocate has traditionally belonged to nursing. A review of past and present features of nursing reveals that nursing has undergone change paralleling major societal changes. Yet, in the main, these societal changes have not "changed" nursing's problems but have only accentuated many of the problems nursing has faced since at least the turn of the century.

Nursing has shown a longstanding concern for consumer rights in health care. One indication of this concern was the issuance of a Patient's Bill of Rights in 1959. Indications of nursing's concern for the patient's right to be informed, to be respected, to participate in decision-making, and to have equal access to health care were evidenced in nursing literature long in advance of the time when it was fashionable to show such concern. But in spite of the ardent advice from nursing leaders and nursing educators, it would seem that nursing has been almost immobilized in acting on these concerns, by an inability to grapple with the problems of nursing itself.

Conclusions

Growing demands for protection of consumer rights are symptomatic of an imbalance between the broader goals of society and the individual's autonomy. While a counter-balancing influence has been attempted through human rights legislation, consumerism strategies, and community develop-

ment processes, a considerable imbalance continues to exist.

Rapid changes in the health care system, brought about by technological gains, have changed the quality of personal care and concern the patient experiences. To those health care providers who naively believe they are already serving the consumer's interests, demands of consumers of health care for rights have come as somewhat of a shock.

The issues which have been raised regarding consumer rights to health care, and rights in health care, are not transitory. They are, rather, reflective of an outstanding need to return the "caring" dimension to health care. Ignoring these issues is to invite backlash and to neglect an opportunity to develop the body of nursing knowledge.

Open dialogue among health care providers and society is vital, in order to dispel the uncertainties surrounding many of the complex issues of consumer rights such as the right of informed consent and the right to refuse treatment. It is beyond the capability of any one profession to shoulder the burden of these difficult decisions, nor is it sensible to dump the responsibility on consumers as though it were solely their problem.

While a general disillusionment with consumer participation has occurred, the principles underlying consumer participation are sound. Continued attention must be directed toward finding methods to put these principles into practice in a variety of situations.

Greater attention to consumer education is vital. Consumer education about the health care system to effect meaningful participation

in planning and evaluating health services, is essential. Equally important is education directed at promoting and maintaining personal health. In the patient role, education about the treatment plan, the rules and regulations of the organization, and a greater clarity of expectations are needed to personalize care.

More equal access to health care is part of a broader societal concern for equality in the provision of many services. Health professionals must be challenged to lead the way in devising means for more equitable distribution of scarce resource.

The development of the patient representative should serve as a reminder to all health providers that our system of care has become large, complex, and unmanageable when, in fact, the actual recipient of care requires a formal representative.

Given that problems within nursing interfere with nursing's ability to be responsive to consumer rights, resolution of such problems is imperative. For those nurses who have not felt the compulsion to act on these problems for other reasons (e.g., status, professionalism) a current compelling incentive must be to act in the interests of the patient/the consumer.

Caught in our present health care system, the consumer experiences an "annihilation of his decision-making powers."[1] Nurses are reminded that the patient has a right to those decision-making

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[1]Sr. Thomas More Bertels, Keynote Address - 1975 Alberta Hospital Association Convention, Edmonton, Alberta.

powers, and are urged to recognize that patients have rights which must not be taken from them.[1]

There are many means to ensure that the consumer is able to retain and exercise his rights. Specific for nursing these include: a renewed interest in health education and health promotion; a collaborative-collegial team relationship amongst doctor, nurse, and all other health professionals; an increased sensitivity to patient needs; a willingness to speak on behalf of the patient when that is to his benefit; a greater respect for patients' wishes in relation to treatment and research; a greater concern for patient confidentiality; a willingness to encourage a more active patient role commensurate with patient abilities; a willingness to be involved with consumers in planning and evaluating health care; and a willingness to expand and adapt nursing functions in accordance with consumer needs and the expertise the nurse might bring to bear upon those needs.

Education about consumer rights is required by all nurses. Orientation programs, in-service education programs, and continuing education programs must make provision for planning and implementing education programs aimed at careful examination of all areas of consumer rights.

Nurses must then begin to speak up individually and collectively for the consumer. In order to do so they must not only have a clear

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[1]Louis M. Thrasher, "Judicial/Legal Aspects," in Proceedings: National Symposium on Patients' Rights in Health Care," (Washington, D.C.: U.S. Department of Health, Education and Welfare, 1976): 20.

perception of the issues, but be united in their conviction, and accept the necessity of the political action required to create a more responsive, consumer-oriented system.

To the extent that the nurse returns to a patient-side role, the patient advocacy function becomes a logical extension of nursing care regardless of the presence of a specific new worker who represents patients. Indeed, the future viability of nursing rests upon a resumption of the patient advocacy role. Consideration should be given to establishing a clinical specialty in nursing related to patient advocacy in order to assist nurses, by role-modeling and in-service education, to re-assume the consumer/patient advocacy role.

On the basis of these several conclusions, it is the overall conclusion of this author that it is imperative that nurses act now to implement consumer rights in health care and in nursing. Failure to act is to jeopardize the consumer's realization of his rights in health care, and to jeopardize the future development of the nursing profession.

Recommendations

While it is recognized that all health care providers must implement consumer rights in health care, and while the majority of the following recommendations could apply equally to all health care providers, apart from nine general recommendations, the focus has been directed primarily to nursing in specific recommendations for implementation of consumers rights in health care and in nursing.

General Recommendations to all Health Care Providers, Policy-Makers, Planners, and Evaluators.

1. That serious attention be given to consumer rights protection and promotion.
2. That efforts be directed at structuring a system of health care based on consumer needs.
3. That, given the dominance of the medical profession in the present health care system, special attention be directed toward the education of physicians in consumer rights issues, trends, and problems; and furthermore, that medical school curricula include a greater emphasis on both hummistic and legal education.
4. That consumer health education efforts be intensified.
5. That careful surveillance of the computerization of patient/consumer records be conducted to safeguard confidentiality.
6. That efforts be directed at finding effective means to put the principles of consumer participation into practice in health care planning and evaluation.
7. That greater public involvement be sought on decisions regarding rights of the mentally ill and rights of the dying.
8. That patient/consumer evaluation of personal hospital and community health care be encouraged by formal as well as informal mechanisms.
9. That all health care providers, policy-makers, planners, and evaluators seek means of increasing their sensitivity to consumer needs.

10. That immediate attention be given to an examination of patient advocacy needs to determine the extent to which the patient representative model adequately fulfills the needs of patient advocacy.

Specific recommendations to Nursing Educators

11. That every effort be made to further sensitize nursing students to clients' needs.
12. That consumer rights issues, trends, and problems be incorporated as an integral part of nursing curricula.
13. That adequate provision be made for the inclusion of legal education in nursing curricula.
14. That consumers be involved in the classroom and clinical instruction of nursing students.
15. That greater effort be directed at providing nursing students with role models of nurses who have reached a healthy and workable compromise between bureaucratic and professional values, based on the interests of the consumer.
16. That serious consideration be given to training clinical nurse specialists in patient advocacy.
17. That teaching materials be developed on consumer rights issues, trends, and problems in health care.

Specific recommendations to Nursing Service Administrators

18. That consumer rights be discussed at all orientation sessions for new employees, and be the subject of in-service education programs for all employees.

19. That policies be evolved specific to each nursing service department related to consumer rights concerns such as informed consent, patient participation in care, patient evaluation of care, etc.
20. That consumer evaluation of nursing care be systematically instituted as soon as possible, by formal as well as informal mechanisms.
21. That nurses support nursing audit procedures to improve nursing care, and that audit criteria include consumer rights implementation in nursing care.
22. That supervisors of nurses create a climate conducive to consumer rights protection and promotion by their example and teaching.
23. That nursing directors actively negotiate structural changes within the organization that would allow for healthier physician-nurse-patient relationships.
24. That consumer/patient advocacy needs be evaluated systematically by nursing service personnel.

Specific Recommendations to Nursing Service Practitioners

25. That individual nurses educate their patients regarding consumer rights.
26. That nurses stimulate patient participation in planning and implementing care.
27. That nurses re-assume a patient advocacy function.

Specific Recommendations to Nurse Researchers

28. That emphasis in nursing research be directed toward studies which evaluate the effects of nursing care, and consumer rights implementation in nursing care.
29. That research be undertaken which is directed to describing patients' advocacy needs.
30. That protection of the rights of the research subject become an overriding concern of all nurse researchers, and that nurse researchers find ways to ensure that the subject/consumer is fully informed.

Specific Recommendations to Professional Nursing Associations

31. That consumer rights issues become a priority concern of nursing associations, commencing immediately, and extending over an initial five-year period: e.g., dialogue with other professions, government, consumer groups, etc.; formulation of a comprehensive policy on consumer rights; determination of a comprehensive critical path; etc.
32. That membership be educated regarding issues, trends, and problems in consumer rights protection and promotion via newsletters, articles, conferences, workshops, and other means.
33. That leadership be exercised by nursing associations in speaking against consumer rights violations and in favor of sound consumer rights practices.
34. That a thorough examination of the consumer/patient advocacy function be undertaken immediately in order to provide guidance to nursing service personnel, and to develop guidelines with regard to patient advocacy.

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APPENDIX A

STATEMENT ON A PATIENT'S BILL OF RIGHTS

AMERICAN HOSPITAL ASSOCIATION

AMERICAN HOSPITAL ASSOCIATION

A PATIENT'S BILL OF RIGHTS

The American Hospital Association Board of Trustees' Committee on Health Care for the Disadvantaged, which has been a consistent advocate on behalf of consumers of health care services, developed the Statement on a Patient's Bill of Rights, *which was approved by the AHA House of Delegates February 6, 1973. The statement was published in several forms, one of which was the S74 leaflet in the Association's S series. The S74 leaflet is now superseded by this reprinting of the statement.*

The American Hospital Association presents a Patient's Bill of Rights with the expectation that observance of these rights will contribute to more effective patient care and greater satisfaction for the patient, his physician, and the hospital organization. Further, the Association presents these rights in the expectation that they will be supported by the hospital on behalf of its patients, as an integral part of the healing process. It is recognized that a personal relationship between the physician and the patient is essential for the provision of proper medical care. The traditional physician-patient relationship takes on a new dimension when care is rendered within an organizational structure. Legal precedent has established that the institution itself also has a responsibility to the patient. It is in recognition of these factors that these rights are affirmed.

1. The patient has the right to considerate and respectful care.

2. The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person in his behalf. He has the right to know, by name, the physician responsible for coordinating his care.

3. The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include but not necessarily be limited to the specific procedure and/or treatment, the medically significant risks involved, and the probable duration of incapacitation. Where medically significant alternatives for care or treatment exist, or when the patient requests information concerning medical alternatives, the patient has the right to such information. The patient also has the right to know the name of the person responsible for the procedures and/or treatment.

4. The patient has the right to refuse treatment to the extent permitted by law and to be informed of the medical consequences of his action.

5. The patient has the right to every consideration of his privacy concerning his own medical care program. Case discussion, consultation, examination, and treatment are confidential and should be conducted discreetly. Those not directly involved in his care must have the permission of the patient to be present.

6. The patient has the right to expect that all communications and records pertaining to his care should be treated as confidential.

7. The patient has the right to expect that within its capacity a hospital must make reasonable response to the request of a patient for services. The hospital must provide evaluation, service, and/or referral as indicated by the urgency of the case. When medically permissible, a patient may be transferred to another facility only after he has received complete information and explanation concerning the needs for and alternatives to such a transfer. The institution to which the patient is to be transferred must first have accepted the patient for transfer.

8. The patient has the right to obtain information as to any relationship of his hospital to other health care and educational institutions insofar as his care is concerned. The patient has the right to obtain information as to the existence of any professional relationships among individuals, by name, who are treating him.

9. The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to participate in such research projects.

10. The patient has the right to expect reasonable continuity of care. He has the right to know in advance what appointment times and physicians are available and where. The patient has the right to expect that the hospital will provide a mechanism whereby he is informed by his physician or a delegate of the physician of the patient's continuing health care requirements following discharge.

11. The patient has the right to examine and receive an explanation of his bill regardless of source of payment.

12. The patient has the right to know what hospital rules and regulations apply to his conduct as a patient.

No catalog of rights can guarantee for the patient the kind of treatment he has a right to expect. A hospital has many functions to perform, including the prevention and treatment of disease, the education of both health professionals and patients, and the conduct of clinical research. All these activities must be conducted with an overriding concern for the patient, and, above all, the recognition of his dignity as a human being. Success in achieving this recognition assures success in the defense of the rights of the patient.

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APPENDIX B

CONSUMER RIGHTS IN HEALTH CARE

CONSUMERS' ASSOCIATION OF CANADA

CONSUMER RIGHTS IN HEALTH CARE

I Right to be informed

1 — about preventive health care including education on nutrition, birth control, drug use, appropriate exercise

2 — about the health care system including the extent of government insurance coverage for services, supplementary insurance plans, the referral system to auxiliary health and social facilities and services in the community

3 — about the individual's own diagnosis and specific treatment program including prescribed surgery and medication, options, effects and side effects

4 — about the specific costs of procedures, services and professional fees undertaken on behalf of the individual consumer

II Right to be respected as the individual with the major responsibility for his own health care

— right that confidentiality of his health records be maintained

— right to refuse experimentation, undue painful prolongation of his life or participation in teaching programs

— right of adult to refuse treatment, right to die with dignity

III Right to participate in decision making affecting his health

— through consumer representation at each level of government in planning and evaluating the system of health services, the types and qualities of service and the conditions under which health services are delivered

— with the health professionals and personnel involved in his direct health care

IV Right to equal access to health care (health education, prevention, treatment and rehabilitation) regardless of the individual's economic status, sex, age, creed, ethnic origin and location

— right to access to adequately qualified health personnel

— right to a second medical opinion

— right to prompt response in emergencies

APPENDIX C

SOCIETY OF PATIENT REPRESENTATIVES OF THE AMERICAN HOSPITAL ASSOCIATION

I. Patient Representative : A Descriptive Definition

II. Patient Representative Programs : Services to Individuals and Families

PATIENT REPRESENTATIVE

A DESCRIPTIVE DEFINITION

The patient representative's primary assignment is to serve as the liaison between patients and the institution as a whole and between the institution and the community it serves. They provide a specific channel through which patients can seek solutions to problems, concerns and unmet needs.

As the patient's advocate they enable patients and families to obtain solutions to problems by acting in their behalf with administration or any department or service, coordinating among departments if necessary and recommending alternative policies and procedures in order to improve service to patients.

As the institution's direct representative, they interpret its philosophy, policies, procedures and services to patients, their families and visitors.

Besides the value of patient satisfaction with personalized service in the bureaucratic system, the hospital benefits by having a team member who can

- take the time necessary to listen to the problem.
- bring the patient's perception of services to the attention of staff and administration.
- research a procedural problem through all the departments that may be involved.
- follow through until a satisfactory solution is found.

In order to be effective the patient representative must be able to cross departmental lines and work with staff at all levels.

PATIENT REPRESENTATIVE PROGRAMS

Services To Individuals and the Institution

The following are guidelines and may be modified to suit the needs of the individual institution.

Services to Individuals

The patient representative program seeks to communicate and demonstrate to the patient and his family, personnel and the community the concern and responsiveness of the institution in meeting the health needs of each individual by

- seeking out those individuals who have problems or questions about the services provided by the institution.
- talking to patients to identify the sources of difficulty in obtaining service.
- determining an appropriate course of action to provide optimum care.
- negotiating institutional red tape on behalf of individuals.
- providing information about services and interpreting the institution's policies and procedures.
- making appropriate referrals to other departments and services within the facility and in the community.
- providing followup to ensure that satisfactory service has been rendered.

Services to the Institution

As the institution's direct representative to patients, the Patient Representative Program provides the channel through which the hospital can respond to needs and concerns of the patients. This can be achieved by

- providing a centralized and consistent patient grievance mechanism.
- providing a central source for information and referrals.
- developing a profile of patient experience and perceptions.
- pinpointing problem areas and staff attitudes which may signal a need to review some aspect of service.
- researching and documenting obstacles to the delivery of service where indicated and recommending change in policies and/or procedures.

A Patient Representative Program allows for more effective utilization of administration and other staff by

- reducing the number of people to whom the patient must explain problems, complaints and requests for service.

- handling special situations for which no mechanism has been established.

- interpreting policies, procedures and services of the hospital.

Because she crosses departmental lines and works with staff at all levels, the Patient Representative can identify problems in inter-departmental communication and help to expedite their resolution.

Through in-service education the Patient Representative can bring to staff an awareness of the patient's perception of the hospital experience, thereby contributing to improved staff attitudes.

By increasing patient satisfaction, a Patient Representative Program enhances the hospital's public image.

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